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## ABSTRACT

This report describes a federally funded project designed to meet the needs of culturally diverse children with special health care needs and their families in New York. The goal was to establish a model program that would demonstrate that the quality of life for culturally diverse children with special health needs and their families would be enhanced and strengthened by linking: (1) case management for children with special health care needs and their families, and (2) community-based self-help/mutual support programs. The project funded development of models for the delivery of case management services to children with special health care needs and their families in 11 countries and in New York City, New York. Case management models had these goals: to develop a policy statement of the need for culturally competent programs; to identify culturally diverse populations within their areas; to provide special outreach services to culturally diverse populations; and to train staff in cultural competency. Self-help clearinghouses worked to enhance self-help/mutual support to culturally diverse families of children with special health care needs. In addition to training clearinghouse and case management project staffs in cultural competency, the project implemented a series of seminars, called Partners in Policy Making, to provide leadership training to parents as a way of empowering culturally diverse families in the care of their children. Twenty-four appendices are attached to the report and include: a directory of New York self-help/mutual support services for children with special health needs; guidelines for creating a local self-help/mutual support group, in English and Spanish; evaluation reports of training sessions; and materials developed by the clearinghouses. (CR)

**FINAL REPORT:**

**Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children  
with Special Health Needs and Their Families**

**MCJ - 367034**

**Bureau of Child and Adolescent Health  
New York State Department of Health  
October 1, 1994**

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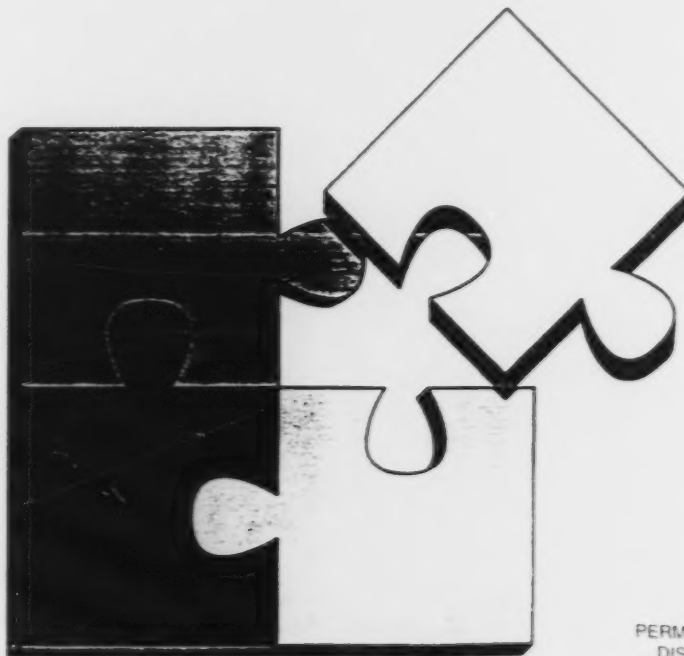
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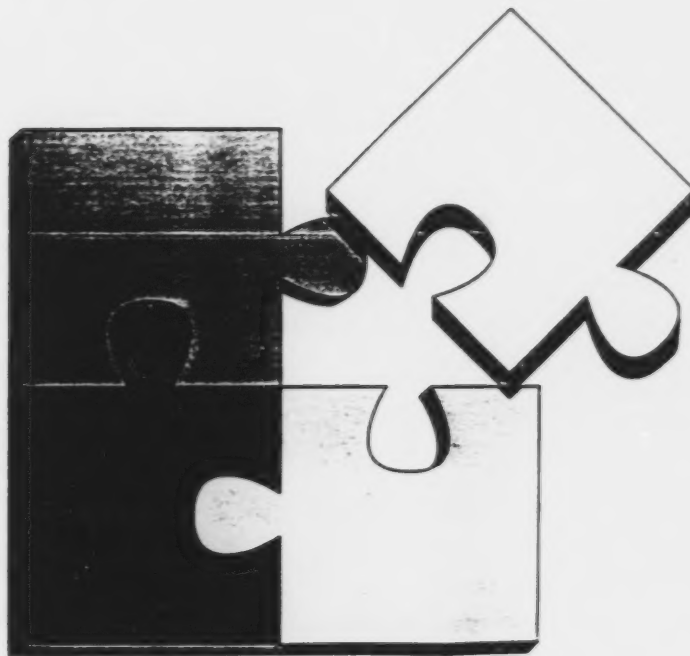
“

My situation with Matthew makes me feel like a Coretta Scott King or a Dr. Shabazz. This is your road in life, to lead... to speak. You're going to champion the people. It is that kind of parallel.

— Marcia Callender, parent

”

*Excerpt from an interview conducted with Marcia, one of the culturally diverse parents with whom Partners in Health worked.*



New York State Department of Health  
Bureau of Child and Adolescent Health

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**Final Report for Maternal and  
Child Health Improvement Projects**

|                                |                                                                                                                           |
|--------------------------------|---------------------------------------------------------------------------------------------------------------------------|
| Project Title:                 | Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families |
| Project Number:                | MCJ-367034                                                                                                                |
| Project Director:              | Mary Huber, MA                                                                                                            |
| Grantee:                       | NYS Department of Health and Health Research, Inc.                                                                        |
| Address:                       | Health Research, Inc.<br>66 Hackett Blvd. (3rd Floor)<br>Albany, NY 12208                                                 |
| Phone Number:                  | (518) 431-1200                                                                                                            |
| Project Period:                | From: 10/1/90 to 9/30/94                                                                                                  |
| Total Amount of Grant Awarded: | \$538,620                                                                                                                 |

**I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V  
MATERNAL AND CHILD HEALTH (MCH) PROGRAMS:**

Relationship to Title V, Purpose, Needs and Problems the Project Addresses

Partners in Health (PIH) was funded as a SPRANS Grant under the program priority Field Initiated. It is a project of the New York State Department of Health, Bureau of Child and Adolescent Health, which operates the state's Title V program entitled the Physically Handicapped Children's Program and other programs for children with special health needs.

The Omnibus Budget Reconciliation Act of 1989 (PL 101-239) requires states to improve the service system for children with special health care needs (CSHCN)



and their families by promoting services that are family centered, community based, culturally competent, and effectively coordinated. These goals are further emphasized in Healthy People 2000. These mandates recognize that families are the primary caregivers of children with special health care needs. Therefore, parents must be full participants in all decisions related directly or indirectly to the care of their children.

#### Problem Statement

The New York State Department of Health (NYS DOH) documented barriers that prevented CSHCN from receiving optimum care in a 1986 review of its Physically Handicapped Children's Program. It found that families had to make decisions about complex health care issues in settings that could shift daily from home, to hospital, to community. Further, the report recognized that medical devices alone are not sufficient; social and emotional support systems that are culturally sensitive can play a significant role in ensuring positive health outcomes of appropriate care. The Association for the Care of Children's Health, in its 1987 publication Family-Centered Care for Children with Special Health Care Needs, presents eight major components of family centered care, among which is the tenet that state programs should encourage and facilitate parent-to-parent support, also known as "self-help/mutual support."

Many factors mitigate against promoting parent to parent support. New York's rural and culturally diverse families often encounter barriers to involvement with other parents. There are many disease specific parent groups for the most common disorders, which provide valuable assistance to member families. Unfortunately, they can fragment efforts to provide services for all children with special health needs by creating competition for scarce resources. Also, they often fail to focus on the essential responsibility of parents as primary caregivers and primary decision-makers in

all aspects of care. Parents whose children have a low-incidence disorder remain unconnected. The current system fails to capitalize on the fact that parents of children with special health needs have many more similarities than differences. These and other circumstances call for a systematic and creative methodology for meeting the generic needs of all families.

Further, there are systemic issues that call for a concerted effort on the part of many families. For example, the Physically Handicapped Children's Program (PHCP) is not mandated at the county level. Consequently, as local budgets shrink, local PHCPs are in jeopardy. Parents can advocate for the programs when cutbacks are proposed. To effect these changes, parents need to increase their familiarity with systems development, policy issues and decision makers so they can provide a strong voice for programs that serve all children with special health care needs. To overcome some of these barriers, PHCP, with funding from the MCH Services Block Grant, established models for the delivery of case management services to children with special health care needs and their families in eleven counties and in New York City.

In addition, after participating in the MCHB-sponsored conference, "Cultural Perspectives in Service Delivery for Children and Families with Special Needs," PHCP identified a need to (1) implement the case management program in a culturally competent manner and (2) include parent and community participants who represent diverse cultural and socioeconomic groups in state planning, program development and implementation. Having identified these goals, each PHCP case management program set out to:

- Develop a clear policy statement of the need for culturally competent programs;

- Identify culturally diverse populations within their areas;
- Provide special outreach services to culturally diverse populations; and
- Train staff in cultural competency.

Cultural competency is particularly important in New York State, where approximately 32 percent of all children are culturally diverse, and as many as 18,000 to 36,000 may be severely disabled (Child and Adolescent Health Profile: New York State, 1987). All families of children with special health needs must become educated consumers so they can gain access to available services, develop the ability to obtain new services in the midst of ever-changing needs, and maintain assertiveness in working with the formal health care system on behalf of their children. The challenges are even more daunting for families of cultural diversity where problems of language, cultural patterns of interaction and disenfranchisement from society's resources may create many additional barriers to obtaining care. Families can be strengthened by assisting them to create community-based self-help/mutual support networks, an egalitarian and culturally competent informal support system.

#### Regional and National Significance of Project

Partners in Health forged a unique combination of disparate elements that are available to many state Title V programs. For example, more than twenty states have Developmental Disabilities Planning Councils that implement training to enable parents to influence public policy decisions that will enhance their children's care. Twenty states have regional or statewide clearinghouses which are set up in the community as places where people can learn about self-help/mutual support and find out about the self-help resources in their areas. The clearinghouses match interested people with an

existing group or network or help others start a new group or network. Other Title V programs can use them to link parents with each other. Most states have schools of higher education with which they can cooperate to obtain additional resources from MCHB to train service providers. All states have Early Intervention Programs (the State's Part H program for children from birth to three) that can provide resources for cooperative program planning, implementation, and professional development.

Partners in Health is of regional and national significance in another way. Due to changing demographics that point to a population in the United States that is increasingly diverse, the issue of improving the delivery of services to culturally diverse families has national significance. This is true not only for families who have children with special health needs, but for all areas of public health. Thus, the lessons learned from this project to increase cultural competence for families who have children with special health needs have application across the spectrum of public health concerns.

#### Potential for Strengthening the MCH Services Block Grant Programs in New York State

In general, Partners in Health demonstrated a method for engaging consumers of services, in particular those who are culturally diverse, as partners in policy making across the range of MCH programs. This project was the first time a concerted effort was made to recruit and train culturally diverse consumers to collaborate with the MCH program in assuring that current programs at the local level maintain or, better still, increase their efforts in providing services to children with special health care needs. The project also highlighted for all MCH programs the paradigm shift that is taking place in all health care programs, from a helping model in which professionals

are the experts with solutions that patients must accept and implement to one in which consumers and professionals work together to define the problem and create solutions that may involve a number of other parties. In addition, lessons learned in the area of cultural competency were shared with the AIDS Institute, the Lead Program, and the recently established Office of Minority Health in the New York State Department of Health, through workshops, technical assistance or individual consultation.

Links to Other SPRANS Projects:

- In New York State, the project worked with the Genetics Network of the Empire State (GENES), a SPRANS project of MCHB Genetics Services Branch on several activities. These included: identifying culturally diverse families who became involved in training programs; identifying support networks for inclusion in the statewide directory; providing workshops at a GENES meeting; and publicizing the project in the newsletter of the GENES project.
- The Partners in Health project director participated at national conferences for SPRANS recipients in all four years of the project. Each of the meetings contributed knowledge that was immediately transferred to the program. For example, at the 1991 meeting in New Orleans, the project director participated in the Cultural Competency Work Group, and through contacts made there, identified trainers for workshops on cultural competency that Partners in Health sponsored in New York State. Similarly, at the 1993 conference conducted in Baltimore, the project staff learned of Family Voices, a group organized to ensure that the needs of CSHCN are considered in proposed national health care reform. The project sponsored one of its founders, Ms. Julie Beckett, to come to New York State. This appearance increased parent involvement with Family Voices statewide.

- Also attending the 1993 SPRANS conference was a parent staff member.

Through the parent networking that took place, she developed an interest in attending the National Parent Network conducted in Chicago, Illinois, May 29-31, 1993. Grant funds supported her attendance at the meeting, a project of the Association for the Care of Children's Health, and subsequently, the staff member became one of the Northeast Regional Representatives for the Network.

- The Partners in Health project director assisted in developing the proposal for the National Maternal and Child Health Resource Center on Cultural Competency for Children with Special Health-Care Needs and Their Families and has benefitted from a mutual exchange of information with the Center.

- Partners in Health contributed an article to the Fall 1992 issue of Child Link, the national publication for SPRANS grant recipients. The article provided other state programs for CSHCN with some practical suggestions for program development in family centered, culturally competent care. Staff and parent consultants presented findings from this three-year effort at the 1994 SPRANS conference (see Appendix 17 for a copy of the article).

- The project director and a parent staff member attended an intensive four-day training session sponsored by the SPRANS-funded National Center on Parent Directed Family Resource Centers conducted July 23-26, 1992. Information from that meeting provided the impetus for continuing to emphasize the importance of parent involvement to systems change.

- Other SPRANS projects have provided extensive information resources that have informed project activities. These include: National Center for Youth with Disabilities, New England SERVE. National Center for Education in Maternal and



Child Health, Project Copernicus, and the Wingspread Conference, "Culture and Chronic Illness: Raising Children with Disabling Conditions in a Culturally Diverse World."

## II. GOALS AND OBJECTIVES:

The goal of Partners in Health was to establish a model program that would demonstrate that the quality of life for culturally diverse children with special health needs and their families would be enhanced and strengthened by linking two relevant elements of the service delivery system: (1) case management for children with special health care needs and their families and (2) community-based self-help/mutual support programs. Partners in Health sought to develop model partnerships between self-help clearinghouses and the case managers for the Physically Handicapped Children's Program in order to increase the accessibility of self-help/mutual support for culturally diverse children with special health needs and their families. The program also sought to increase the number of culturally diverse families of children with special needs that participate in self-help/mutual support interventions.

A second goal of Partners in Health was to critically evaluate the project in order to assess the usefulness of the strategies that were employed and to guide future efforts in the field of culturally competent programs for families of CSHCN. Since the lessons learned through Partners in Health will no doubt be useful to many workers in the field of public health, the program's third goal was to disseminate project findings.

A linkage between case management and self-help/mutual support unites two approaches which are based on a common premise -- that is, that the community is the most effective locus for empowering people to take control of their lives, to contribute

to their own care as well as that of others (McKnight, 1987; Koop, 1987). It is in community that an individual's capacities can be recognized as strengths that contribute to the common good. Both case management and self-help/mutual support ask people to work together, to share responsibilities. The goals of both are to be responsive to changing needs, to provide immediate, practical assistance, and to place a human face on the helping process. The end result, empowerment, enables people to influence decisions that affect their lives. Ultimately, the proposal strove to develop partnerships: the partnership between the case management program and self-help, which in turn would facilitate the development of a partnership between parents and professionals and parents with each other.

### III. METHODOLOGY

The project consisted of two components: activities at the self-help clearinghouses and activities of the central office; they will be briefly mentioned here and more fully described in subsequent sections.

#### Self-Help Clearinghouses

As conceptualized in the proposal, the majority of project activities were to be carried out by the local self-help clearinghouses. They were to operate within the confines of strict geographic boundaries (county lines). The services provided, as well as the influence of the project, would be primarily limited to four counties. One clearinghouse was located on Long Island and served both Nassau and Suffolk counties, while the other two were located in Niagara and Schenectady counties. These sites were selected because they each had a Physically Handicapped Children's Case Management Program, represented demographic diversity within the state (urban, suburban and rural), and had residents who were culturally diverse.

In order to lay the groundwork for developing self-help/mutual support for culturally diverse families, self-help clearinghouses first increased their efforts to enhance self-help/mutual support for all chronically ill children and their families.

Each clearinghouse:

- developed lists of current groups or networks;
- maintained lists of families interested in mutual support activities;
- provided technical assistance to individuals interested in starting new groups or networks;
- provided technical assistance on group or network development.

With these basic clearinghouse tasks completed, clearinghouses made a special effort to enhance self-help/mutual support for culturally diverse families. As organizations which are mainstream agencies, the emphasis on reaching out to culturally diverse families required a redirection of energy. This involved a multi-pronged approach based upon the principles and methods of community organizing, i.e., learning about the culturally diverse community, hiring culturally diverse staff, developing relationships with key persons in the community so that they could maintain ownership of the process, and marketing the effort to key groups.

To provide culturally diverse families with information about the resources available at the Clearinghouse, staff distributed brochures, newsletters and flyers, broadcast radio ads, and placed newspaper print ads. To disseminate the information described above, clearinghouse staff engaged in various public awareness activities such as fairs, open houses, conferences, and presentations. A full account of the amount of material distributed (more than 27,000 pieces) and the type of activities engaged in can be found in Appendix 1 in the sections Materials Disseminated and

Public Awareness Activities. Samples of the materials are located in Appendices 20 - 22.

Examples of innovative approaches to this task include the development of an interactive theater presentation by the Schenectady County Self-Help Clearinghouse. The script was performed by the youth group, Girls, Inc., and stressed traditional self-help/mutual support themes. The presentation addressed the fear and isolation that a parent may feel if their child has special health care needs, parent's lack of knowledge about how to cope, and the benefits of talking to others who are going through similar experiences. The event, which drew twenty culturally diverse families, was co-sponsored by a day care center located in the culturally diverse community.

The Long Island Self-Help Clearinghouse devoted extensive resources reaching out to the Hispanic community in both counties, which has grown considerably in the last decade. Specifically, it hired a Hispanic staff person; translated its brochures and basic information on self-help/mutual support into Spanish; identified Hispanic media outlets and issued press releases to them; and worked with Hispanic churches and human service organizations to identify families whose children have special health care needs.

The Niagara County Self-Help Clearinghouse first hired a Native American from the Tuscarora Reservation to serve as a bridge to families there, and then hired an African American mother of a child with special health care needs to work with the black community. Staff nurtured the development of a parent advocacy network whereby, after participating in a series of seminars presented by legal experts and parent advocates, families served as advocates for other families in the areas of education and health.

### Central Office

The Central Office was to carry out few initiatives separate from the local projects. As Partners in Health evolved and its broader goals and objectives of parent empowerment became integrated with PCHP and other MCH programs within the Bureau of Child and Adolescent Health, the function of the central office grew to encompass an increasingly expansive sphere of activities, which were unforeseen when the project was conceived. These activities were statewide and conducted with a thrust toward systems change. The activities of each of the major program components will be described here briefly.

The following list indicates the extensive training activities the project undertook. Details are explained in the narrative that follows.

|                                                                                                     |
|-----------------------------------------------------------------------------------------------------|
| <b>Training Sessions for Professionals:</b>                                                         |
| Introductory Training Session for self-help clearinghouses and case management projects (June 1991) |
| Cultural Competency - three regional conferences (September 1991)                                   |
| Self-Help/Mutual Support - three regional conferences (June 1992)                                   |
| Cultural Competency - three regional conferences (September 1992)                                   |
| Maximizing the Helping Relationship - five regional conferences (September 1993 and Spring 1994)    |
| <b>Training Sessions for Parents:</b>                                                               |
| Partners in Policy Making (with NYS Developmental Disabilities Planning Council)                    |
| Four sessions in New York City                                                                      |
| Three sessions each in Albany and Batavia                                                           |
| Two sessions in Long Island (in cooperation with the State Education Department)                    |

### Training in Cultural Competency and Self-Help/Mutual Support

Training in cultural competency began in June 1991 for the staff of the clearinghouses and case management projects in the counties identified as Partners in



Health sites. The focus on cultural competency expanded to include all PHC Case Management Projects and the State's Early Intervention Program when the project conducted three regional conferences on cultural competency in September 1991 and again in September 1992. In 1993, the director contributed to two regional conferences entitled, "Maximizing the Helping Relationship," which was presented at three additional sites in 1994. In June 1992, the project director ran three regional training conferences on the topic of self-help/mutual support. A complete discussion of the efforts is contained in the evaluation reports for these sessions, which are included in Appendices 2-5, and in Section V of this report, entitled Results/Outcomes.

#### Partners in Policy Making

Partners in Policy Making consisted of a series of seminars designed to empower parents of children with special health needs. Conceived by the Developmental Disabilities Planning Council (DDPC) in Minnesota, Partners in Policy Making has become an innovative national model of leadership training for people with disabilities, parents and family members. As such, it is a perfect vehicle for implementing Partners in Health's goals of empowering culturally diverse families in the care of their children. While NYS DDPC had offered the program to families whose primary concern is children with developmental disabilities, families of children with chronic medical problems and physical disabilities often were not included. Partners in Health arranged the training for this audience.

Originally, staff planned only one conference for 50 families in Albany. More than 150 parents throughout the state applied, and each presented compelling reasons to participate. In order to capitalize on this enthusiasm and to provide a means for all to attend, Partners in Health and DDPC sponsored the conference in three areas of the



state. Helping to defray some of the expenses were funds from another Federal MCH Bureau grant, Children with Special Health Care Needs Systems Development.

Staff made a particular effort to engage culturally diverse families in the program. Of the 150 applicants, 141 identified their ethnocultural background. Of that number, 30 were black, 12 Native American, 8 Hispanic, and 1 Asian American.

In order to maximize its impact, Partners in Health selected three training objectives:

- To develop a network of families who have children with physical disabilities or chronic illness;
- To provide network members with advocacy and leadership skills that will enable them to influence policy decisions that affect their lives; and
- To provide participants with information and communication resources that will assist them in being supportive to each other.

In partnership with DDPC and the Physically Handicapped Children's Program, Partners in Health designed an agenda that combined presentations on issues related to children with special health needs; small group work that encouraged parents to recognize their own strengths and develop action plans; and skill development that would assist them in advocacy activities, working within the legislative processes at the state and county level, and talking to community leaders.

This skill development is particularly crucial in New York State where the Physically Handicapped Children's Program is not mandated at the county level. Consequently, as local government budgets shrink, several counties have already cut back on the program, and some counties are discussing ending the service altogether. Parents are now alerted to this possibility and have stated that they will advocate for maintaining or expanding the level of service.

At the conference, Partners in Policy Making, parents expressed a need to be able to connect to other parents on a one-to-one basis for support and information. As a result, Partners in Health modified a form developed by the Association for the Care of Children's Health (ACCH) for its *Parent Resource Directory*. A new section was added to the questionnaire which asks families if they have experience working with a number of ethnocultural groups in order to assist culturally diverse families who are seeking resources. Copies of the two publications (one for New York City and Long Island, the other for the rest of the state) are attached in the Appendices 7 and 8.

Partners in Policy Making (PIP) consisted of ten sessions held in cooperation with NYS Developmental Disabilities Planning Council. Four of these sessions were held in New York City, three in Albany, and three in Batavia. In addition, two sessions were held on Long Island in cooperation with the State Education Department.

#### Fundraising and Evaluation

The project director's fundraising activities began by applying to the Centers for Disease Control for funding to encourage self-help/mutual support groups at local county level units for all MCH programs. Unfortunately, this project was not funded. Funds were obtained from the Early Intervention Program to provide major support for the training in cultural competency and self-help/mutual support mentioned above. In addition, the Maternal and Child Health Bureau, through its continuing education division, provided funding for "Maximizing the Helping Relationship," whose purpose was to encourage family centered, culturally competent care. The Developmental Disabilities Planning Council became another sponsor of activities by funding two years of Partners in Policy Making. The Maternal and Child Health Bureau also provided funding for a new four-year grant which builds on the foundation of Partners

in Health in a new SPRANS grant, The Family-Professional Training Institute, whose goal is to foster family-professional collaboration.

Another activity of the central office was to design and implement evaluation tools concerning the outcome of the project. They are described specifically in the evaluation section.

### Publications

In addition to evaluation reports of training sessions, Partners in Health developed three significant publications. The first two are "The New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families," which was first published in February of 1992 and updated with a second edition in April of 1994. They are located in Appendices 9 and 10. This directory is indexed by county and provides listing of support groups in adjacent states and Canada. The third major publication, "Partners in Health: Self-Help Groups for Families of Children with Special Health Needs," provides guidelines and suggestions for creating a local self-help/mutual support group. Available in Spanish and English, the manual has as one of its primary audiences leaders of community based organizations (CBOs) within culturally diverse communities who have the interest and resources to assist families of children with special health care needs by establishing a parent support network, or responding in other creative ways. The topics discussed include getting started, setting goals and objectives, recruiting other members, meeting for the first time, involving the community, publicizing, and obtaining more information. Copies in English and Spanish are located in Appendices 11 and 12.

#### IV. EVALUATION

The major components of the evaluation process consisted of questionnaires filled out by: 1) parents who came into contact with the project through calls to the clearinghouses; 2) participants in Partners in Policy Making seminars; and 3) participants in all training sessions. In addition, the clearinghouses filed quarterly reports on program activities to the central office. At the conclusion of the project, independent evaluators conducted phone interviews with case management program directors. The project director conducted a focus group with clearinghouse personnel and also conducted extensive interviews with two culturally diverse parents who were particularly active with project activities. Each will be discussed below.

##### Parent Satisfaction Questionnaire

Interviewers administered a Parent Satisfaction Questionnaire to parents who called each of the local self-help clearinghouses (a copy is attached in Appendix 13). The telephone survey requested some basic demographic data, as well as information on parents' experiences with local self-help clearinghouses, case management programs, and self-help/mutual support networks. Interviewers established the ethnicity of the caller, caller's relationship to child, child's age, child's disease status, and the county of residence. Caregivers were asked whether or not they had joined the case management program and, if they had not joined, the interviewer attempted to establish why the caller had not joined. Caregivers were also asked whether or not they had joined a self-help/mutual support network. A large portion of the Parent Satisfaction Questionnaire was devoted to determining the extent to which parents benefitted from joining self-help mutual support networks. Parents were asked if they had made any new relationships, learned more about their child's illness, or met others

to whom they could turn to for help. They were also asked whether they had learned about practical things that they could do to help themselves or their child, and if they had learned about parent or financial resources. The interviewer also sought general comments and recommendations.

The Parent Satisfaction Questionnaire also obtained information concerning children's illnesses. Caucasian and culturally diverse respondents were equally likely to report diagnoses of cancer, and equally likely to report emotional/behavioral disorders. This suggests that, at least with regard to this survey population, the availability of cancer and emotional/behavioral disorder self-help probably does not explain differences in the proportion of each group joining self-help.

Children of culturally diverse respondents were less likely to be diagnosed with Down syndrome, learning and hearing disorders, and disorders of the central nervous system than were children of Caucasian parents. Culturally diverse respondents were only about half as likely as Caucasians to report these diagnoses. On the other hand, culturally diverse children were 3-times as likely to be diagnosed with asthma and, as might be expected, 13-times as likely as Caucasians to be diagnosed with sickle cell anemia.

#### Partners In Policy Making

Participants in Partners in Policy Making seminars were given questionnaires six to eight months after attending the core program (follow-up sessions were conducted one year after the core). A sample questionnaire is located in Appendix 14. The first block of questions concerned the degree of participant's preparation as an advocate prior to the seminar. Subsequent questions sought to determine the level of advocacy with which the participant became engaged after attending the training. This

included the number of contacts with national, state and local leaders, and public education efforts they undertook through newspapers, television, radio and seminars. The questionnaire inquired about advocacy efforts within a work, school or health care environment. Participants were also asked if they shared information with others, started a support network themselves, or maintained supportive relationships with other parents they met through Partners in Policy Making. The final block of questions determined the number and location of sessions attended. In addition, participants were asked "open" questions in order to record benefits of the seminars which were difficult to classify.

#### Training Seminars

Participants in training seminars completed questionnaires designed to gauge the usefulness of the sessions. These surveys were administered immediately after the sessions. Typically, the respondents assessed on a scale from zero to four, with zero being poor and four excellent, each of the following program components: program content, method of presentation, handouts, and overall evaluation of the session. Participants were also offered several opportunities to respond to open ended questions and to assess the relevance of the session in their work.

Several training sessions (the 1992 series on cultural competency and the 1993 and 1994 sessions on family centered, culturally competent care, "Maximizing the Effectiveness of Helping Partnerships,") also involved respectively a one-year and three month follow-up.

#### Quarterly Reports

To evaluate the activities at each of the clearinghouses, staff filed a quarterly report with the project director. These reports contained information on the number



and race of callers of parents of children with special health care needs. In addition, a chart was kept recording where the parents received information about the clearinghouse. Clearinghouse staff also listed the number and nature of new support groups, type of training and technical assistance provided to communities, materials disseminated, and public awareness activities. These results are summarized in Appendix 1.

At the close of the project, the project director called a meeting of the clearinghouse staff to receive their feedback on the results of the project. The staff reported their opinions on the nature of their relationship with the PHC Case Management Program, the cultural competency of the clearinghouses, the most successful and unsuccessful forms of outreach to culturally diverse communities, the lessons learned for replication and transfer, and the short- and long- term impact of the project. Key findings from this meeting are integrated in the section of this report entitled "Results/Outcomes." A summary of the entire meeting can be found in the booklet, "Report of the Self-Help Clearinghouse Focus Group," which is attached in the Appendix 15.

#### Case Studies

The project director and clearinghouse staff also conducted personal interviews with a select few of the culturally diverse parents of children with special health care needs who participated in some aspect of the project. These interviews were designed to capture the human element of the project. Two types of case studies were conducted. The first consisted of interviewing culturally diverse parents from Long Island who filled out the Parent Satisfaction Questionnaire. The goal was to determine reasons why these individuals participated, or failed to participate, in self-help/mutual

support groups. The second type of case study was conducted with individuals who participated in Partners in Policy Making. These individuals engaged in many empowerment activities after Partners in Policy Making and it was the desire of the project to determine the impact of their participation. The report of these interviews may be found in Appendix 16.

#### Resource Manual

The resource manual, "Partners in Health: Self-Help Groups for Families of Children with Special Health Needs," will be evaluated by surveying the recipients of the manual to find out if it was of assistance to community based organizations and families. The results will be compiled after the completion of this final report as one of the activities of the SPRANS project, "Family-Professional Training Institute."

#### Directory

The original evaluation tool for the directory consisted of a user response form located on the last page of the directory. Although 2,500 copies were distributed, only 5 individuals returned the evaluation. A far more valuable evaluation occurred when staff reviewed the directory with service providers at the three regional meetings on self-help/mutual support. The resultant discussion functioned much like a focus group and produced several valuable suggestions that were incorporated into the second edition, such as the inclusion of information from states contiguous to New York.

### **V. RESULTS/OUTCOMES:**

This section will be organized around the results in three major categories: (1) the partnership between PHC case management and the self-help clearinghouses; (2) central office activities; and (3) the Bureau of Child and Adolescent Health.

### Self-Help Clearinghouses

A complete summary of quarterly reports submitted may be found in Appendix

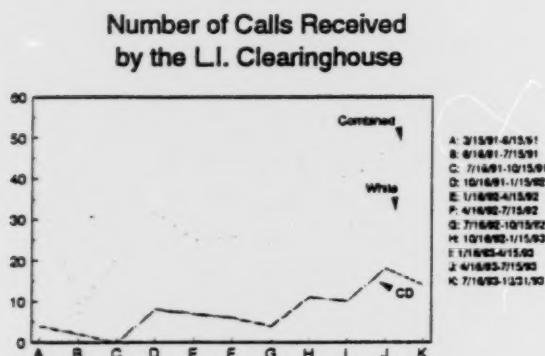
1. The major findings are given here. The following table displays the number and ethnicity of callers to each of the self-help clearinghouses.

**Table 1.** Number and ethnicity of callers to the clearinghouses.

| Year | Long Island                                                                                                     | Niagara                                                                   | Schenectady                                                                |
|------|-----------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|----------------------------------------------------------------------------|
| 1991 | March-December<br>26 Caucasian<br>11 African Am.<br>3 Hispanic<br>59 Unknown<br>3 Called for others<br>77 Total | July-December<br>1 Unknown<br>1 Total                                     | April-December<br>1 Caucasian<br>4 Hispanic<br>113 Unknown<br>118 Total    |
| 1992 | 66 Caucasian<br>10 African Am.<br>13 Hispanic<br>5 Asian<br>31 Unknown<br>8 Called for others<br>133 Total      | 27 Caucasian<br>3 African Am.<br>30 Total                                 | 2 Caucasian<br>197 Unknown<br>199 Total                                    |
| Year | Long Island                                                                                                     | Niagara                                                                   | Schenectady                                                                |
| 1993 | January-October<br>93 Caucasian<br>4 African Am.<br>36 Hispanic<br>1 Asian<br>1 Greek<br>135 Total              | January-June<br>64 Caucasian<br>10 African Am.<br>38 Unknown<br>112 Total | January-September<br>3 Caucasian<br>1 Hispanic<br>133 Unknown<br>137 Total |

Table 1 shows that as clearinghouse increased their public awareness efforts within the culturally diverse community, the number of culturally diverse callers to the self-help clearinghouses increased. The ethnic origin of clearinghouse staff appears to have been a major factor influencing the ethnicity of callers. For example, when the Long Island Self-Help Clearinghouse replaced an African American with an Hispanic

staff person in October, 1992, there was an immediate increase in the number of Hispanic callers. Graph 1 illustrates the increase in culturally diverse callers over time.



The clearinghouses promoted the formation of new self-help/mutual support networks. Among all families, not just those who are culturally diverse, six new support groups formed in Niagara County, one formed in Schenectady, and eight formed on Long Island. It was also learned that culturally diverse families were forming their own support groups, without prompting from the local clearinghouses. For example, one of the evangelical churches on Long Island facilitated the development of a prayer group for Hispanic families who have a family member with disabilities. The group, which met in member's homes, combined prayer and social support. In this case, the Spanish-speaking staff from the clearinghouse provided information to members about services available through the formal helping system, especially the PHC Case Management Program.

#### Analysis of Parent Satisfaction Questionnaires

Parent Satisfaction Questionnaires were administered by telephone to caregivers who contacted any of the three self-help clearinghouses during the period of this grant.

(A copy of the questionnaire is located in Appendix 13). Only those parents who provided telephone numbers to the clearinghouses were contacted. A total of 157 questionnaires were received and analyzed. Of these, 130 (82.8%) originated at the Long Island Self-Help Clearinghouse. Another 15 (9.4%) were received from Niagara, and 12 (7.6%) were received from Schenectady. Table 2 (below) compares the volume of questionnaires received from each site to the estimated number of children with special health needs residing in the area. As Table 2 indicates, the distribution of questionnaires received was very similar to the distribution of severe chronic illness in the areas surveyed.

**Table 2.** Number of Parent Satisfaction Questionnaires received from the self-help clearinghouses, compared to estimated number of children with severe chronic illness in the area served.

| Self-Help Clearinghouse | Quest. Recv'd | Percent of Quest. Recv'd | Est. CSHCN <sup>1</sup> | Percent of Est. CHN |
|-------------------------|---------------|--------------------------|-------------------------|---------------------|
| Long Island             | 130           | 82.8                     | 13725                   | 83.5                |
| Niagara                 | 15            | 9.6                      | 1233                    | 7.5                 |
| Schenectady             | 12            | 7.6                      | 1484                    | 9                   |
| Total                   | 157           | 100.0                    | 16442                   | 100.0               |

The clearinghouses covered several counties. The Long Island Clearinghouse, for example, received calls from Nassau and Suffolk, while the Niagara Clearinghouse received calls from Niagara and Erie. The callers' reported residences are set forth in Table 4, below.

<sup>1</sup> The estimated number of children (0-19 Years) with a severe chronic illness, defined as: (1990 census population for ages 0-19) x 0.02. The Schenectady Clearinghouse served Albany County.

**Table 4.** Respondent's reported county of residence.

| <u>County<br/>of Residence</u> | <u>Calls<br/>Received</u> | <u>Percent<br/>of Total</u> | <u>Est.<br/>CSHCN</u> | <u>Percent<br/>of Total</u> |
|--------------------------------|---------------------------|-----------------------------|-----------------------|-----------------------------|
| Suffolk                        | 82                        | 52.2                        | 7380                  | 42.1                        |
| Nassau                         | 34                        | 21.7                        | 6345                  | 36.2                        |
| Niagara                        | 14                        | 8.9                         | 1233                  | 7.5                         |
| Albany                         | 12                        | 7.6                         | 1484                  | 9.0                         |
| Erie                           | 1                         | 0.6                         | -----                 |                             |
| Unknown                        | 14                        | 8.9                         | -----                 |                             |
| Total                          | 157                       | 99.9                        | 16,442                | 100.1                       |

It would appear that Nassau County residents were greatly under-represented in the survey (22% of survey vs. 36% of the total CSHCN population). However, most of the respondents that did not provide their county of residence were Long Islanders; they may have come from Nassau County, and this may have contributed to the shortfall. Another possibility is that Suffolk residents are more interested in self-help than residents of Nassau, and hence more likely to telephone the Long Island Clearinghouse.

One hundred and forty-five (92.4%) respondents reported caring for one child, while ten (6.4%) cared for two children. In two (1.3%) cases, the number of children cared for could not be determined, but is assumed for purposes of analysis to be one. Of the 167 children cared for, 55 (33%) were age three or younger.

As expected, respondents reported a broad range of diagnoses, with some children suffering from multiple disorders. When children were classified according to principle illness, the breakdown was as follows:



**Table 5.** Classification of illnesses (CD = Culturally Diverse).

| Class                              | White Freq. | Percent of Total (White) | CD Freq. | Percent of Total (CD) |
|------------------------------------|-------------|--------------------------|----------|-----------------------|
| CNS Disorders (not Cerebral Palsy) | 50          | 29.9                     | 10       | 22.7                  |
| Cerebral Palsy                     | 31          | 18.6                     | 4        | 9.1                   |
| Learning Disorders                 | 22          | 13.2                     | 5        | 11.4                  |
| Asthma                             | 11          | 6.6                      | 6        | 13.6                  |
| Emotional or Behavioral Disorders  | 11          | 6.6                      | 3        | 6.8                   |
| Autism                             | 6           | 3.6                      | 0        | 0.0                   |
| Cancer                             | 6           | 3.6                      | 0        | 0.0                   |
| Down Syndrome                      | 6           | 3.6                      | 1        | 2.3                   |
| Sickle Cell Anemia                 | 6           | 3.6                      | 5        | 11.4                  |
| Other                              | 18          | 10.7                     | 10       | 22.7                  |
| Total                              | 167         | 100.0                    | 44       | 100.0                 |

Almost 30% of the children in this survey were diagnosed with a disorder of the central nervous system. The most common disorder reported was cerebral palsy, afflicting 18% of the children. Cerebral palsy was the most common diagnosis among the children of Caucasian callers. Cerebral palsy was only half as common among CD callers. The most common disease reported by CD callers was asthma.

The percentage of culturally diverse callers to the self-help clearinghouse that joined a support network (9%) was far smaller than the percentage of culturally diverse callers who joined a case management program (39%). This suggests that

culturally diverse respondents may have been able to take advantage of case management more easily than self-help. In contrast, 36% of the Caucasian callers joined a self-help/mutual support-network, while only 26% joined case management programs.

Culturally diverse respondents were 50% more likely than Caucasians to report joining a case management program, but only one quarter as likely to report joining a self-help/mutual support network. It is possible that culturally diverse parents encounter barriers in pursuit of self-help that they do not encounter in pursuit of case management -- barriers which are not encountered by Caucasians. An alternative explanation is that culturally diverse parents contacted by the clearinghouses determined that financial assistance and other concrete benefits provided by case management were more useful than self-help.

Respondents were asked why they had not joined self-help/mutual support networks. The most popular response was "not interested" (n=27, 17%). Other popular responses included "no families to connect with" (n=15, 9.6%), and "forming my own network" (n=10, 6.4%). Culturally diverse parents were more likely than Caucasians to report "lack of interest" as their reason for not joining a self-help group. Other common statements among culturally diverse caregivers included: "I'm not in need of it" and "I was looking for financial help."

The clearinghouse staff at Long Island believes that the culturally diverse families with which she worked are too overwhelmed to be interested in support groups. This conclusion comes from her grass-roots work with families who were contacting the human service organizations for concrete services, such as payment of child's medical care through PHCP. This may explain the much higher rate of joining

the case management program which leads families to direct services. One of the reasons so many families may have connected to the concrete services was because the case management program, which did not have culturally diverse staff, worked with the Spanish-speaking clearinghouse staff to provide outreach to families. At the conclusion of the grant, in acknowledgement of the benefit of having access to bilingual resources, the PCH Case Management Program in Suffolk County contracted with a Hispanic agency to provide ongoing outreach and translation services for the Hispanic community.

In addition, information gathered from case studies of culturally diverse callers on Long Island indicated that no support group for sickle cell anemia existed in Suffolk County which has a child population of over 410,000. A sickle cell group in Nassau County was apparently not conveniently located. Suffolk County residents made it clear that the distance was too far to travel. The absence of a sickle cell group in Suffolk County may have reduced the proportion of culturally diverse parents reporting that they had joined a self-help group.

Despite the few cases of culturally diverse families joining self-help/mutual support networks, it is important to note the substantial percentage that received services through the case management program. By encouraging enrollment in case management, Partners in Health facilitated the delivery of necessary services to culturally diverse children and their families.

Respondents reported very favorably on the benefits of self-help/mutual support. Parents were asked several questions concerning their experiences with self-help. The results are summarized in Table 6.

**Table 6.** Answers to survey questions concerning parent's experiences with self-help/mutual support networks.

| Survey Question                                                                                    | Response |    | Percent Responding Favorably |
|----------------------------------------------------------------------------------------------------|----------|----|------------------------------|
|                                                                                                    | Yes      | No |                              |
| Did you meet other people you could talk to about your child's illness?                            | 36       | 3  | 92.3%                        |
| Did you learn more about your child's illness?                                                     | 29       | 10 | 74.4%                        |
| Did you learn from other parents about practical things you can do to help yourself or your child? | 27       | 11 | 71.1%                        |
| Did you learn about financial assistance you didn't know about before?                             | 8        | 4  | 66.7%                        |
| Do you feel that you have a place to turn to when you are in need that you didn't have before?     | 36       | 2  | 94.7%                        |
| Did you make any new relationships?                                                                | 35       | 3  | 92.1%                        |
| Have you referred any other parents to the support network?                                        | 25       | 13 | 65.8%                        |
| Through membership, have you helped another parent?                                                | 23       | 13 | 63.9%                        |

These observations are in agreement with the literature on the benefits of self-help/mutual support. Many of the benefits listed above, such as learning more about a child's illness, result in a direct improvement in the quality of treatment, and thus in health status.

Report of the Self-Help Clearinghouse Focus Group (See Appendix 5 for a more complete review.)

As stated earlier, through her outreach to the Hispanic community, the Long Island staff person discovered churches sponsoring special prayer meetings for families of children with special health needs. These prayer meetings played a role very much like a self-help/mutual support network. Given the effectiveness of the support groups formed independently through church groups, perhaps a worthwhile approach in the future would be to develop a program to work with statewide religious organizations to foster self-help/mutual support.

Although the efforts of the staff at the clearinghouses were successful in reaching some, it is still very difficult to reach the target audience. We know the clearinghouse followed steps outlined in the proposal to develop culturally competent self-help clearinghouses, to learn about the culturally diverse community, and to work with key people in the community. On Long Island and in Schenectady, staff listed churches and community centers to be the most productive in reaching the culturally diverse community. The Niagara staff felt she was unable to reach culturally diverse families. That may be in part due to the lower number of culturally diverse families in Niagara County. She cited an example of a woman who wished to start an Hispanic support group, but could not find enough families interested.

When asked to characterize unsuccessful means of outreach, staff listed several approaches. In Schenectady, the staff person found running an announcement on a Community Cable Access Station was a waste of time. No callers to the clearinghouse ever cited that as a source of information about PIH. In Niagara County, the staff person cites a three-part series of sessions they designed to train parents to become

parent advocates. Although thirty people participated, it failed to attract culturally diverse parents, even though that was the explicit target audience. At Long Island, the staff person felt that sending packets to people containing instructions as to how to begin a support group did little good. Despite calling to confirm receipt of the packets, little or no initiative occurred.

At the focus session, staff mentioned several times that the culturally diverse are often involved in self-help through extended families. These extended families provide support, financial resources and baby sitting; all services and benefits often associated with government agencies or as a result of support group networking. It may be important to redefine self-help in these environments.

The clearinghouse found that the extensive, grassroots outreach they performed identified people with a great amount of need. These needs overwhelmed the part-time staff at the clearinghouse, who often assisted by providing translation services for forms, and so forth. Often severely disenfranchised, families could not obtain the most basic services for their children. Thus, self-help/mutual support was not a priority in their lives. In the future, the self-help clearinghouses might concentrate more of their efforts on providing technical assistance to community based organizations within the culturally diverse community, so that they may have skills to develop support groups.

Based on the results of the focus group that included the self-help clearinghouse coordinators and the telephone survey that was conducted with the directors of the case management projects, it is clear that the project forged linkages between the two programs as it said it would. Specifically, PHCP administrators reported that one of the key benefits derived from this program was a database of



appropriate support networks that could be shared between case management and self-help clearinghouse staff. Often the case managers would call for information on specific self-help/mutual support networks. It was impossible to track individuals or families which may have joined a support network as a result of this referral.

A major outcome of the Partners in Health project is the increased cultural competency of the clearinghouses. In Niagara County, the PIH staff person feels that cultural competency would not be an issue at all without Partners in Health. Today, all eleven employees of the agency have attended at least one cultural awareness session. In addition, at different stages of the project, the clearinghouse hired a Native American and an African American. In Schenectady, the mere fact that the PIH staff person hired was a black person points to an awareness of the need for cultural competency. In addition, more African Americans, as well as an Asian now sit on the Clearinghouse's Board of Directors. The staff person believes Partners in Health enlightened the executive director to the issue of cultural competency. At the Long Island Clearinghouse, the hiring of an Hispanic, again, is a step towards cultural competency. This staff person points out that while it is important to translate materials into Spanish, it is equally important to have someone able to speak Spanish when working with the Hispanic community.

#### Central Office Activities

One effective methodology for involving culturally diverse individuals in self-help/mutual support that Partners in Health sponsored involved bringing families together under the auspices of a training program, Partners in Policy Making, to learn about the benefits of self-help/mutual support through an experiential process.

The results and outcomes reported in this section will be based on participants from ten sessions held in New York City, Albany and Batavia. A total of 103 parents attended these sessions. A follow up questionnaire was mailed to the participants several months after the sessions. Fifty-nine of these surveys were returned, a 57 % response rate. Table 7 records the ethnicity of the participants and questionnaire respondents.

**Table 7.** Ethnicity of Partners In Policy Making participants.

| Ethnicity         | Participants | Questionnaire Respondents |
|-------------------|--------------|---------------------------|
| Caucasians        | 68 (66% )    | 33 (55.9%)                |
| African Americans | 27 (26.2%)   | 17 (28.8%)                |
| Native Americans  | 6 (5.8%)     | 2 (3.4%)                  |
| Hispanic          | 2 (1.9%)     | 1 (1.7%)                  |
| Unknown           | 0 (0%)       | 6 (10.2%)                 |
| Total             | 103          | 59 (57%)                  |

To analyze the results of these sessions it is enlightening to compare the culturally diverse percentages with that of the Caucasians and take note of the aggregate as well. It must be remembered that these results came from a voluntary response of the questionnaire and people who have been active since Partners are more likely to return the questionnaire than those who were not. Table 8 summarizes responses to key activities from the 59 participants who returned the questionnaire.

**Table 8.** Response rates for key activities for PIP participants. Percentages reflect percent for that category.

| Activity                                                    | Culturally Diverse | Caucasian | Aggregate |
|-------------------------------------------------------------|--------------------|-----------|-----------|
| Number of Participants                                      | 20                 | 33        | 59        |
| Contact with State, Local or National Officials             | 16 (80%)           | 29 (88%)  | 51 (86%)  |
| Office Visit Contact                                        | 9 (45%)            | 11 (38%)  | 21 (41%)  |
| Testified at a Public Hearing or Served on a Committee      | 15 (75%)           | 18 (55%)  | 37 (63%)  |
| Advocated in a School, Work or Health Setting               | 20 (100%)          | 26 (79%)  | 51 (86%)  |
| Advocated in School Setting                                 | 17 (85%)           | 25 (76%)  | 46 (78%)  |
| Advocated in Work Setting                                   | 7 (35%)            | 6 (18%)   | 14 (24%)  |
| Advocated in Health Care Setting                            | 11 (55%)           | 15 (45%)  | 29 (49%)  |
| Indicated PIP left them very prepared to become an advocate | 16 (80%)           | 18 (55%)  | 37 (63%)  |
| Engaged in Public Education Efforts                         | 15 (75%)           | 21 (64%)  | 40 (68%)  |
| Obtained More Appropriate Services                          | 16 (80%)           | 21 (64%)  | 39 (66%)  |
| Started a Support Group                                     | 7 (35%)            | 8 (24%)   | 15 (25%)  |
| Maintained Supportive Relationships with Participants       | 10 (50%)           | 13 (39%)  | 25 (43%)  |
| Shared Information with Others                              | 20 (100%)          | 31 (94%)  | 55 (95%)  |
| Listed Other Benefits                                       | 18 (90%)           | 23 (70%)  | 43 (73%)  |

From the above summary, one notices that culturally diverse parents took an active role in enhancing health status following the sessions. The culturally diverse parent participants were recruited from sources in contact with health advocacy groups. It was felt that these participants were more acculturated than the culturally diverse families who did not attend, and it was believed that these parents could then be ambassadors to the more disenfranchised families.

Empowerment as a result of PIP included an awareness that each parent can make a difference for themselves, their child, and their community. Some parents felt they obtained the assertiveness and confidence to act, and that they gained the knowledge they are not alone, that other parents experience the same frustration. Parents learned that New York State has programs designed to help families, and that the State needs input from parents as to the nature of their struggles and needs.

Some concrete example of empowerment activities among all families, including those who are culturally diverse, include: two parents became parent consultants for the NYS Early Intervention Program; one parent joined the county health department's local Early Intervention Coordinating Council; one parent taught advocacy skills to others who then gave a presentation at a legislative luncheon; a parent served on the parent advisory board for State Foster - Adoptive Parents, Inc.; a parent organized a campaign against a preschool which would not admit physically challenged children; a parent was nominated as a candidate member of the NYS Developmental Disabilities Planning Council; one participant stated that through letters from parents and friends, money was reinstated for a Physically Handicapped Children's Program; two participants began working with the Queens Parent Resource Center, a program directed by parents for children with special needs.

Activities since the questionnaires include: one participant is working with the State legislature regarding legislation requiring harmful vaccinations; a foster parent has been recruiting other foster parents of children with special needs to be advocates for their child; two participants have become the parent member of the local Early Intervention Coordinating Council; three participants have formed a network for parents experiencing any kind of difficulty with children; one participant now sits on

the ADA Advisory Committee and the Accessibility Committee in her county; another parent worked with Erie County on accessibility issues for the World University Games in August 1993; and one participant is now a member of an advisory board of a hospital that serves children with cancer.

Project staff believe that those who attended Partners in Policy Making participated in an experiential learning process regarding mutual support that enabled them to transfer the knowledge to real life. An example of the impact Partners in Policy Making had can be seen in the story of one of the parents, M. Callender. Ms. Callender attended Partners in Policy Making in September 1992. As a result of her participation at Partners in Policy Making, other parents recommended her for the position of parent consultant to the Early Intervention Program, the Part H Program in New York State. She was hired for that position in November. In December, her son Matthew passed away, but his mother decided to maintain her personal and professional commitment to children with special needs. In April, she attended another meeting of PIP in which the focus was health care reform. Staff suggested that families write to the lead policy maker on health care reform, Hillary Rodham Clinton, and tell their stories about obtaining care for their children. Ms. Callender took the initiative and wrote to Ms. Rodham Clinton of her experience with Matthew. The President was so moved by her account of Matthew's ordeal and passing, he requested that Ms. Callender attend a public policy meeting he was conducting in New York City. This meeting was covered by national television news programs, and Ms. Callender appeared with the President on the front page of many newspapers nationwide.

In a personal interview with the project director, Ms. Callender asserted that she would never have written that letter without Partners in Policy Making. Partners gave her self-confidence, and more importantly, the belief that one person can make a difference. In the construction of the letter, Ms. Callender followed guidelines learned at the PIP seminars. In her position with the Part H program and her own initiatives, she has had a profound impact on other culturally diverse families. Many parents continue to recognize her from her visit with the President and tell her that she was the inspiration for becoming more involved in making changes. Ms. Callender estimates that she has come in contact in some way with at least one thousand families since that event, the majority of whom are culturally diverse. See Appendix 16 for the complete text of the interview.

The model for Partners in Policy Making (commitment to action as a pre-requisite for attending; overnight stays to increase camaraderie; homework assignments; reports back to the group of accomplishments) was so successful that this approach will be used for the training sessions designed for the SPRANS grant the Bureau is currently undertaking for family-professional collaboration.

Although many aspects of this project were successful, it was clear that the approach was not accessible for all families. For example, although the application material was translated into Spanish, only eight Hispanic families applied to attend. Further, the application form in length alone (three pages) assumed a high literacy level (See Appendix 17). In order to reach families who may be reluctant to go through such a daunting process, Partners in Health established a relationship with the State Education Department (SED) to offer a modified version of Partners in Policy Making through SED's five Adult Centers for Comprehensive Education and Support



Services (ACCESS). These centers were established to offer coordinated, family-centered adult education opportunities that include English as a Second Language, literacy, employment, and self-sufficiency services for adults, as well as classes in parent education and child development. While dad is learning to read, his daughter may be two classrooms away in a play group. They may join each other for an afternoon snack or at story time.

The ACCESS sites agreed to host Partners in Policy Making for two day-long sessions in the easternmost end of Long Island, which is isolated from services and training opportunities. They recruited families from their program, and provided transportation and child care as encouragement for families to attend. The first such program was conducted in the fall of 1993 and attracted a multicultural audience, including a representative from the Native American Shinnecock Reservation, the first contact for the project with that tribe.

As a result of this effort, the ACCESS site sponsored a support group for the families. This effort will be replicated in the other four ACCESS sites in 1994 as part of the Family-Professional Collaboration project.

#### Training Sessions for Professionals

Partners in Health sponsored five training seminars for professionals entitled:

- (1) Introductory Training Session -- June 1991
- (2) Developing Culturally Competent Programs for Children with Special Health Needs, Part One -- 3 regional sessions; January 1992;
- (3) Empowering Families Through Self-Help/Mutual Support --3 regional sessions; December 1992;
- (4) Developing Culturally Competent Programs for Children with Special Health Needs, Part Two -- 3 regional sessions September 1993.

(5) Maximizing the Helping Partnership - 2 sessions in the fall of 1993, 3 sessions in spring 1994.

The primary audience for the introductory training seminar was staff of the Physically Handicapped Children's Program Case Management Projects and self-help clearinghouses in the project's four demonstration counties. The introductory training seminar, held in August 1991, was organized to provide both didactic and experiential learning on key topics such as engaging culturally diverse communities in self-help/mutual support, developing partnerships between case managers and self-help clearinghouses, and providing information in a format that could be replicated at local sites. In general, the session provided a useful starting point for initiating project activities. (For a complete evaluation, see "Evaluation Report: Introductory Training Session," which is found in Appendix 2.)

The other seminars were similarly well-received, with most aspects of training receiving "excellent" or "good" grades. Complete reports on these sessions, including outcomes, are found in Appendices 3-5. A recent concrete example of the impact of the training on cultural competency is reported in correspondence of August 19, 1994, to Ms. Nancy Kehoe, Director of the State's Title V Program. The translation of program materials into Spanish by one of the PHC Programs is viewed by the program director as progress on the cultural competence continuum. (See Appendix 23 for the correspondence).

#### Accomplishments within the New York State Department of Health.

##### Bureau of Child and Adolescent Health

Some unintended organizational outcomes occurred within the Bureau of Child and Adolescent Health which operates the programs for children with special needs in

New York State. The project served as a springboard for accessing funds to support additional efforts such as training in cultural competency, training parents as partners in policy making and increasing family-professional collaboration. The project also served as a catalyst for improving the internal organization and coordination of programs for CSHCN. Frequent discussions took place among the staff of the PHCP, the state's System Development Initiative, the Early Intervention Program, and children with special health care needs assessment initiative in order to reduce fragmentation and maximize resources. In addition, the project served as a catalyst in increasing interagency coordination, especially with the NYS Developmental Disabilities Planning Council which previously did little programming for families with children with special health care needs. The project served as a vehicle of increasing coordination with the School of Public Health, in the writing, receiving and implementation of a grant on the topic of family-centered, culturally competent care. Another outcome was the appreciation for the role that parents may play as staff to a program for children with special health care needs.

The principle emphasis of this grant on cultural diversity was like a luge course from which the project could not veer. So despite potential barriers, such as fears that families would not join support groups, or language, or worries about the high cost of translating materials into a second language, the project had to maintain its track. By virtue of having to stay on course, the project did in fact learn a great deal which will serve as the underpinnings for all future efforts working with families of children with special health care needs, especially those who are culturally diverse.

Number of Individuals Identified by Racial and Ethnic Group who were (1)  
Served, or (2) Trained During Each Year of the Project

The following numbers represent a conservative estimate of those served or trained. The project has counted only those with which it had direct contact, not those, for example, who may have benefitted from the ripple effect of parents helping other parents, which was documented in the previous discussion, or from the publication of manuals and directories. (T=Trained, S=Served)

|                        | 1990-91   |          | 1991-92    |            | 1992-93    |            | 1993-94    |            |
|------------------------|-----------|----------|------------|------------|------------|------------|------------|------------|
|                        | T         | S        | T          | S          | T          | S          | T          | S          |
| Asian/Pacific Islander | 0         | 0        | 1          | 2          | 1          | 5          | 2          | 0          |
| Black                  | 11        | 0        | 53         | 27         | 71         | 28         | 26         | 5          |
| American Indian        | 6         | 0        | 15         | 0          | 8          | 7          | 1          | 0          |
| White                  | 51        | 0        | 158        | 42         | 165        | 120        | 218        | 40         |
| Hispanic               | 0         | 0        | 8          | 0          | 4          | 16         | 7          | 25         |
| Other                  | 0         | 0        | 54         | 113        | 0          | 282        | 0          | 50         |
| <b>TOTAL</b>           | <b>68</b> | <b>0</b> | <b>289</b> | <b>184</b> | <b>249</b> | <b>458</b> | <b>254</b> | <b>120</b> |

#### VI. PUBLICATIONS/PRODUCTS:

Following is a list of publications/products resulting from the Partners in Health Program. Copies of these materials are available from the grantee, unless otherwise noted. To obtain copies of materials listed, please contact:

Mary Huber, NYS Department of Health  
Empire State Plaza, Corning Tower, Room 208  
Albany, New York 12237-0618  
(518) 474-6781

**Articles/Reports**     *Audience: CSHCN Policy Makers and Staff*

*Evaluation Report: Training Session for Developing Culturally Competent Programs for Children with Special Health Needs Part 2 (1993).*

*Evaluation Report: Training Session for Developing Culturally Competent Programs for Children with Special Health Needs Part 1 (1992).*

*Evaluation Report: Training Sessions for Empowering Families through Self-Help/Mutual Support (1992).*

*Final Report: Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families (1994).*

*Partners in Health Promotes Parent-to-Parent Support Networks Child Link, Fall 1992.*

**Manuals**

*Partners in Health: Self-Help Groups for Families of Children with Special Health Needs (1994).* This manual is designed for leaders of community based organizations in culturally diverse communities.

**Directories**

*The Family Resource Guide: A Guide for Services and Supports for Families Who Have a Child with a Disability (1993).* Compiled for Niagara and Erie counties. Copies are not available.

*New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and their Families.* Editions of 1992 and 1994.

*Parents as Resources: A Compilation of Parent Resource Lists from Partners in Policy Making, New York City (1992).*

*Parents as Resources: A Compilation of Parent Resource Lists from Partners in Policy Making, Upstate Region (1993).*

**Evaluation Tools**

Parent Satisfaction Questionnaire. The purpose of this tool was to gather information from parents who called the local self-help clearinghouses. It requests basic demographic data, as well as information on parents' experiences with local self-help clearinghouses, case management programs, and self-help/mutual support networks.

Report of the Self-Help Clearinghouse Focus Group (1993).

Presentation graphics that describe the evaluation results of Partners in Policy Making.

#### **Case Studies**

Interview with M. Callender conducted by Mary Huber (1993).

Interview with Joyce Frances conducted by Mary Huber (1994).

#### **Program Materials**

Brochures on self-help/mutual support in English and Spanish produced by self-help clearinghouses.

Public awareness brochures on Partners in Health in English and Spanish produced by self-help clearinghouses.

Fact sheet and application materials in English and Spanish for "Partners in Policy Making."

#### **National Presentations**

1993, 1994 National Maternal and Child Health SPRANS Conference; and

1993, 1994 American Public Health Association

### **VII. DISSEMINATION/UTILIZATION OF RESULTS**

Information about Partners in Health's activities and products have been shared with a variety of audiences both in New York State and nationwide. The audience varied according to the purpose of the product and potential utilization of results. For example, the evaluation reports that described the process and results of the numerous training sessions (Appendices 3-5) were sent to staff of local health units who attended the sessions so that the report would serve as a reminder of the information covered at the workshop and as a review of the action plans that participants developed as a follow-up to the training. Collating all the action plans developed at the workshops, which were conducted regionally, also provided a mechanism for demonstrating to each local health unit how colleagues throughout the state approached the same issue.



whether that be developing culturally competent programs, or encouraging the development of self-help/mutual support networks for families. The reports were also sent to administrators of the county programs for children with special health needs in order to inform them of the material staff was learning. Staff of PIH distributed the reports at the annual SPRANS conferences sponsored by Pathfinders and to the National MCH Resource Center on Cultural Competency for inclusion in its data base.

The project distributed the two editions of the *New York State Directory of Self-Help/Mutual Support ...* to both professional and lay audiences. (See Appendices 9 and 10). These included among others the Physically Handicapped Children's Program (PHCP) in all counties, the PHCP Case Management Programs, PHCP Specialty Centers (Title V Centers for Diagnosis and Evaluation of CSHCN), hospitals with pediatric in-patient and out-patient sites, participants at the statewide conference for school health nurses, contact people for the support networks listed in the directory, and the more than 800 families who are on the Bureau's mailing list. The are also regularly distributed at conferences the Bureau conducts for families as part of the SSDI project. The information was also sent to three 800-numbers operated by three state agencies for inclusion in their data bases.

Staff shared lessons learned from the project in an article distributed nationally in *Child Link* (see copy in Appendix 18) and with The Institute for Family Centered Care, which incorporated the information into the manual it is producing for the Federal MCH Bureau on the topic of involving families as advisors to programs for CSHCN. Other opportunities for dissemination occurred in interactions with numerous programs, such as those described on page six of this report and at national

presentations, where at least 20 people from across the country requested and received additional information.

The manual, *Partners in Health*, was distributed widely, especially to culturally diverse families who, through their participation in Partners in Policy Making, have a predisposition to the material and a high recognition of the important role of parent networks in assisting families. In addition, the Long Island Self-Help Clearinghouse distributed the Spanish version on an individual basis through a Latino social services organization. Other copies were distributed to the families employed by the state's Part H program, and professionals who participated in three regional conferences on family centered, culturally competent services, "Maximizing the Helping Relationship." The manual will also be one of the resources distributed for the proposed training program on family-professional collaboration that will be sponsored by the new SPRANS grant, the Family-Professional Training Institute.

Based on the work of this project, the Office of Diversity and Multicultural Services in the NYS Department of Health (DOH) invited the project director to serve on the Department's Cultural Diversity Needs Assessment Work Group. In addition, the project shared information with the director of DOH's Office of Minority Health, which was established recently. The Office was particularly interested in the project's approach to training on cultural competency, and it is anticipated that coordination will continue between project staff and the Office of Minority Health. In fact, the recently appointed Deputy Director served as one of the co-trainers with Richard Roberts, Ph.D., for the second series of statewide trainings on cultural competency which the project conducted in 1992, further facilitating ongoing collaboration. Based on these efforts in the area of cultural competency, the project director will be participating in a

"train-the-trainer" program on cultural diversity sponsored by the Governor's Office of Employee Relations for DOH staff.

Families identified through project activities have served in an advisory capacity to both the Department of Health and to other state agencies, such as the New York State Developmental Disabilities Planning Council. Many have begun to play a key role as consultants to the Family-Professional Training Institute.

In general, one of the most productive utilizations of Partners in Health is that it changed some crucial aspects of New York State's approach and programming for children with special health care needs, in particular its emphasis on the importance of parent to parent support for all families and the initiation of activities related to cultural competency.

#### VIII. FUTURE PLANS/FOLLOW-UP

Many of the activities of the project will be continued, albeit with a different emphasis, through the SPRANS grant, The Family-Professional Training Institute. The concepts of family empowerment, the importance of parent to parent support and cultural competency are overarching themes for the activities of the Institute. Other programs for CSHCN in the Bureau are supporting similar themes. For example, both the CSHCN Needs Assessment Initiative and SSDI are convening focus groups of families to identify key issues that the state and local communities should consider in designing programs for families whose children have special health needs. The Institute will continue to encourage parent to parent support through its newsletter and the continued publication of the *NYS Directory of Self-Help/Mutual Support* .... The post-assessment results of the first five sessions of *Maximizing the Helping*

*Relationship* indicate that the training was beneficial, and the Bureau will seek funds to provide at least four other regional sessions of this workshop to assure that the training is provided statewide.

## **IX. TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE**

Partners in Health experimented with two approaches to develop self-help/mutual support for parents whose children have special health care needs -- one approach took place at the local level through local self-help clearinghouses, the other as a centralized function of the state's Title V programs, but in an era of shrinking resources, states may need to make a choice between the two. It may also be possible for states to contract with a parent organization to provide the parent to parent support that all families of CSHCN need. One of the advantages of locating Partners in Health in the Title V agency was that the project could coordinate with other programs for CSHCN, such as the state's Part H program, and with other state agencies working on similar efforts, such as the Developmental Disabilities Planning Council. Coordination between a state agency and a community based agency often is a formal process of contracts, whereas it can be more efficient between state agencies, since it is "business as usual." Whatever approach is chosen, generally the Title V program will need to find new funds to support such an effort or redirect existing funds to support parent to parent initiatives.

Training service providers on the issue of cultural competency also requires resources dedicated to this initiative. Someone must be available to consider the basics of any adult education program, the who, what, when, why, and where of such an

effort. The challenge is even greater when the topic is such a new one and there are few models to examine for replication, as is the case with cultural competency. Other expenses to consider are the cost for a consultant trainer(s), the development of resource materials, the time involved in organizing the site, publicizing the event, registering participants, and evaluating the program's effectiveness.

The project spent all its federal funds, and raised approximately \$50,000 in additional funding to support project activities.

## CONCLUSION

Perhaps an effective way to capsule the impact of Partners in Health is best stated by a parent, M. Callender, who said in an interview:

*"The thing that I got out of Partners (in Policy Making) was that one person can make a difference, and that one person is also one vote, one letter, one contact with a public official. Any thing one person can do can really help bring about change .... It's about waving a flag, getting on a soapbox, about being part of the system and realizing, indeed, you have a voice that can be heard and it can make a change no matter how little or big it is. You have to be involved."*

## References

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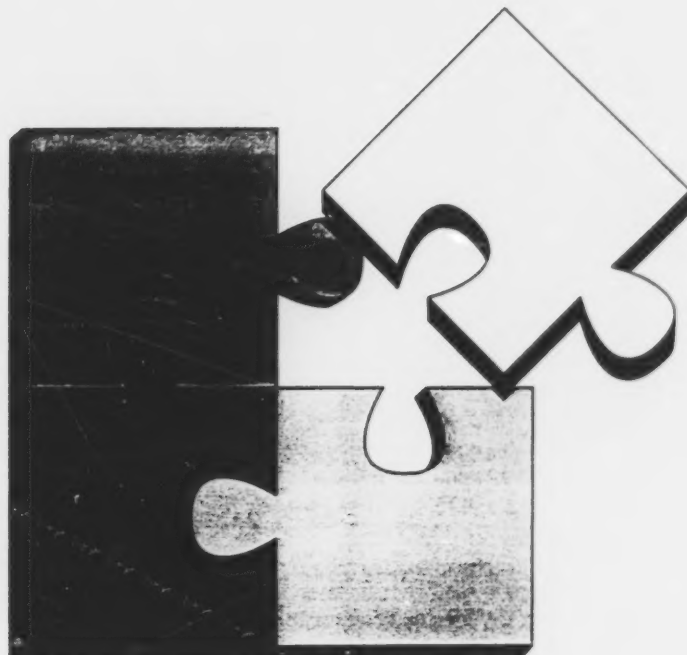
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**Appendix 1**

**Summary of Information  
Submitted in Quarterly Reports  
by Self-Help Clearinghouses**



New York State Department of Health  
Bureau of Child and Adolescent Health

## Niagara County

| Quarter                                                                                                                                    | July-Sep. 1991 | Oct.-Dec. 1991                                                                                                                                                                                             | Jan.-March 1992                                                                                                                                                                                                                                          | April-June 1992                                                                                  |
|--------------------------------------------------------------------------------------------------------------------------------------------|----------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| Form 1:<br>Number & Race of Callers                                                                                                        | Not Available  | 1 Caucasian                                                                                                                                                                                                | None                                                                                                                                                                                                                                                     | None                                                                                             |
| Form 2:<br>Source of Information<br>about the Clearinghouse<br><br>* denotes that totals listed<br>are for the Clearinghouse in<br>general | Not Available  | 1 Hospital                                                                                                                                                                                                 | 3 Clearinghouse Directory<br>27 Previous Caller<br>17 Clearinghouse Newsletter<br>9 Public Agency<br>1 Friend/Relative<br>6 School<br>4 Hospital<br>2 Support Group<br>1 Information Referral Line<br>1 Therapist<br>15 Newspaper/Magazine<br>65 Other * | None                                                                                             |
| Form 3:<br>Number & Nature<br>of new Support Groups                                                                                        | Not Available  | None                                                                                                                                                                                                       | None                                                                                                                                                                                                                                                     | None                                                                                             |
| Form 4:<br>Training & Technical<br>Assistance Provided                                                                                     | Not Available  | None                                                                                                                                                                                                       | None                                                                                                                                                                                                                                                     | None                                                                                             |
| Form 5:<br>Materials Disseminated                                                                                                          | Not Available  | 50 Brochures                                                                                                                                                                                               | 2 News releases<br>1500 MHA Newsletter which<br>contained an article about PIH                                                                                                                                                                           | 2 News releases<br>231 Brochures                                                                 |
| Form 6:<br>Public Awareness Activities                                                                                                     | Not Available  | Presentations:<br>Multi-Cultural Advisory<br>Committee;<br>Print Media:<br>News Releases to area<br>newspapers, cable TV & radio<br>stations;<br>Paid advertisements to Retailer &<br>Metro Community News | Presentations: Visit to Tuscarora<br>Reservation to solicit interest in<br>Partners in Policy Making;<br>Print Media: 2 News releases                                                                                                                    | Presentations:<br>Partners in Policy Making<br>in Batavia; Panelist at camp for<br>special needs |

## Niagara County

| Quarter                                                     | July-Sep. 1992                                                                                                                                                                        | Oct.-Dec. 1992                                                                                                                                                                                                           | Jan.-March 1993                                                                                                                                                                      | April-June 1993                                                                                                                                                                                 |
|-------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number & Race of Callers                         | 14 Caucasian<br>2 Black                                                                                                                                                               | 13 Caucasian<br>1 Black                                                                                                                                                                                                  | 12 Caucasian<br>38 Unknown                                                                                                                                                           | 52 Caucasian<br>10 Black                                                                                                                                                                        |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 12 Clearinghouse Brochure<br>1 Health Department<br>1 Public Agency                                                                                                                   | 6 Clearinghouse Brochure<br>7 Previous Caller<br>1 School                                                                                                                                                                | 1 Clearinghouse Brochure<br>3 Health Department<br>3 Previous Caller                                                                                                                 | 3 Clearinghouse Brochures<br>2 Clearinghouse Letter<br>5 Previous Caller<br>2 Unknown<br>2 Teacher                                                                                              |
| Form 3:<br>Number & Nature<br>of new Support Groups         | Parents of physically<br>challenged children - Erie;<br>Parents of children with<br>disabilities - Orleans;<br>Parents of children with<br>mental/emotional<br>disturbances - Niagara | Parents of emotionally<br>disturbed children - Niagara;<br>Parent Information Exchange<br>and Support Group - Erie;<br>Parents of children with<br>disabilities - Orleans; Self<br>Help support group leader<br>training | Continued facilitation of<br>Parent Advocacy Network;                                                                                                                                | Continued facilitation of<br>Parent Advocacy Network                                                                                                                                            |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Parent Advocacy Training                                                                                                                                                              | Publicity and flyers for three<br>groups; Organizational<br>support to Parent Advocacy<br>Network; Provided financial<br>support for CMP sibling<br>outing and CMP mailing                                               | Sent a self-help information<br>packet to a parent interested in<br>starting a Latino support<br>group; Provided financial<br>support to CMP for mailing;<br>Sponsored legal seminar | Lay Advocacy Legal<br>Training; Publicity for<br>Schools Are for Everyone<br>meeting; Co-facilitated Parent<br>Advocacy Network Meeting                                                         |
| Form 5:<br>Materials Disseminated                           | 530 Brochures<br>800 Newsletters                                                                                                                                                      | None                                                                                                                                                                                                                     | 110 Brochures<br>1200 Newsletters<br>50 Flyers                                                                                                                                       | 425 Brochures<br>1200 Newsletters<br>475 Flyers                                                                                                                                                 |
| Form 6:<br>Public Awareness Activities                      | Radio: Community Link<br>program which highlights<br>local agencies & programs;<br>Print Media: paid<br>advertisement in 2<br>local newspapers                                        | None                                                                                                                                                                                                                     | Presentation:<br>Parent Advocacy Legal Rights<br>Workshop;<br>Other: Sent mailing on<br>Schools Are for Everyone &<br>a technology stimulation<br>presentation                       | Presentations: English as<br>Second Language;<br>Committee on Special Ed.<br>West Seneca Developmental<br>Disabilities Services Office<br>Meeting; Print Media: News<br>release on Safe Meeting |

## Niagara County

| Quarter                                                     | July-Sept. 1993                                                                                           |
|-------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number & Race of Callers                         | 4 Caucasian                                                                                               |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 3 Previous Caller<br>1 School                                                                             |
| Form 3:<br>Number & Nature<br>of new Support Groups         | None                                                                                                      |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Lay Advocacy Legal Training,<br>Sponsored tent party and<br>baseball game for Parent<br>Advocacy Newtwork |
| Form 5:<br>Materials Disseminated                           | 1200 Newsletters<br>429 Family Resource Guides                                                            |
| Form 6:<br>Public Awareness Activities                      | Completed family resource<br>guides                                                                       |

## Schenectady County

| Quarter                                                     | April-June 1991                                                                                                    | July-Sep. 1991                                                                                                                                                                                                                                                      | Oct.-Dec. 1991                                                                                                                                                                     | Jan.-March 1992                                                                                                                  |
|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number &<br>Race of Callers                      | Not Available                                                                                                      | 1 Black Hispanic<br>1 Asian<br>52 Unknown                                                                                                                                                                                                                           | 1 Caucasian<br>3 Black Hispanic<br>61 Other/Unknown                                                                                                                                | 53 Unknown                                                                                                                       |
| Form 2:<br>Source of Information<br>about the Clearinghouse | Not Available                                                                                                      | 2 Clearinghouse Brochure<br>2 Clearinghouse Poster<br>3 Doctor<br>3 Friend/Relative<br>1 Health Department<br>1 Hospital<br>1 Information & Ref. Line<br>3 Newspaper/Magazine<br>9 Previous Caller<br>10 Public Agency<br>14 Telephone Directory<br>5 Other/Unknown | 4 Clearinghouse Brochure<br>9 Friend/Relative<br>2 Newspaper/Magazine<br>15 Previous Caller<br>13 Public Agency<br>1 Radio<br>12 Telephone Directory<br>8 Unknown/Other            | 3 Clearinghouse Brochures<br>1 Friend/Relative<br>15 Previous Caller<br>10 Public Agency<br>10 Telephone Directory<br>14 Unknown |
| Form 3:<br>Number & Nature of<br>new Support Groups         | Not Available                                                                                                      | None                                                                                                                                                                                                                                                                | None                                                                                                                                                                               | None                                                                                                                             |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Not Available                                                                                                      | Assisted in locating a place for<br>the Turner Syndrome Support<br>Group                                                                                                                                                                                            | Provided publicity for the<br>Sickle Cell Society                                                                                                                                  | Technical Assistance<br>provided to the Sickle Cell<br>Society in their membership<br>drive                                      |
| Form 5:<br>Materials Disseminated                           | Not Available                                                                                                      | 400 Brochures<br>885 Newsletters                                                                                                                                                                                                                                    | 60 Brochures                                                                                                                                                                       | 60 Brochures<br>200 Flyers                                                                                                       |
| Form 6:<br>Public Awareness Activities                      | Television: Public service<br>announcements;<br>Other: Urban league fair;<br>Sacred Heart/Proyecto<br>Juvenil fair | Print Media: Article on<br>PIH in local Newspapers;<br>Other: Carver community fair;<br>Sunnyview Awareness Day;<br>Weekly Food Pantry Outreach                                                                                                                     | Presentation: Direct Service<br>Advocates;<br>Television: Sickle Cell<br>Announcement on public<br>access channel;<br>Other: Centro Civico Hispano<br>& Early Childhood Newsletter | Presentation: Partners in<br>Health conference;<br>Television: Local channel<br>announcing conference                            |

## Schenectady County

| Quarter                                                     | April-June 1992                                                                                                                                           | July-Sep. 1992                                                                                                                               | Oct.-Dec. 1992                                                                                                                                                               | Jan.-March 1993                                                                                                                                        |
|-------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number & Race of Callers                         | 26 Unknown                                                                                                                                                | 2 Caucasian<br>52 Unknown                                                                                                                    | 66 Unknown                                                                                                                                                                   | 1 Black Hispanic<br>54 Unknown                                                                                                                         |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 3 Clearinghouse Brochure<br>3 Friend/Relative<br>1 Newspaper/Magazine<br>6 Previous Caller<br>3 Public Agency<br>3 Telephone Directory<br>7 Unknown/Other | 3 Friend Relative<br>1 Newspaper/magazine<br>14 Previous Caller<br>5 Public agency<br>2 Radio<br>1 School<br>14 Telephone Dir.<br>12 Unknown | 2 Clearinghouse Brochure<br>5 Friend/Relative<br>1 Newspaper/Magazine<br>25 Previous Caller<br>15 Public Agency<br>15 Telephone Directory<br>1 Television<br>2 Unknown/Other | 5 Clearinghouse Brochures<br>4 Friend/Relative<br>2 Newspaper/Magazine<br>11 Previous Caller<br>9 Public Agency<br>16 telephone Directory<br>8 Unknown |
| Form 3:<br>Number & Nature<br>of new Support Groups         | Not Available                                                                                                                                             | None                                                                                                                                         | None                                                                                                                                                                         | None                                                                                                                                                   |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Not Available                                                                                                                                             | None                                                                                                                                         | None                                                                                                                                                                         | Ideas on how to start a<br>support group for cancer<br>patients.                                                                                       |
| Form 5:<br>Materials Disseminated                           | 128 Brochures                                                                                                                                             | 77 Brochures                                                                                                                                 | 110 Brochures                                                                                                                                                                | 155 Brochures<br>900 Newsletters                                                                                                                       |
| Form 6:<br>Public Awareness Activities                      | Not Available                                                                                                                                             | Print Media: Display Ad in<br>local newspaper;<br>Other: Swan St. Block Party;<br>Lark Fest; Whitney Young<br>Family Day; PIII Picnic        | Presentation: Display Ad<br>in 2 local newspapers                                                                                                                            | None                                                                                                                                                   |



## Schenectady County

| Quarter                                                     | April-June 1993                                                                                                                                                  | July-Sept. 1993                                                                                                          |
|-------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number &<br>Race of Callers                      | 2 Caucasian<br>57 Unknown                                                                                                                                        | 1 Caucasian<br>22 Unknown                                                                                                |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 4 Clearinghouse Brochure<br>4 Friend/Relative<br>1 Newspaper/Magazine<br>8 Previous Caller<br>17 Public Agency<br>6 Telephone Directory<br>19 Unknown            | 1 Friend/Relative<br>1 Newspaper/Magazine<br>2 Previous Caller<br>3 Public Agency<br>4 Telephone Directory<br>12 Unknown |
| Form 3:<br>Number & Nature of<br>new Support Groups         | None                                                                                                                                                             | Provided consultation for<br>Family United for Supports in<br>Schenectady                                                |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Financial & Legal Assistance<br>for Family United for Support<br>in Schenectady; Aided a<br>Rensselaer group interested in<br>starting a cancer support<br>group | Assisted in searching for legal<br>services for group's<br>incorporation                                                 |
| Form 5:<br>Materials Disseminated                           | 127 Brochures                                                                                                                                                    | 40 Brochures                                                                                                             |
| Form 6:<br>Public Awareness Activities                      | Presentation: PIH/Christ<br>Church Day Care Youth<br>Expression Theater                                                                                          | Other: Display at the<br>Empire State Black Arts<br>Festival                                                             |

## Long Island

| Quarter                                                                                                                            | March-June 1991                                                                                                                                                                                       | June-July 1991                                                                                                                                                                                       | Jul.-Oct. 1991                                                                                                                                                                                                                                                                                                                                                 |
|------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number &<br>Race of Callers                                                                                             | 2 Caucasian<br>4 Black<br>31 Other/Unknown                                                                                                                                                            | 2 Hispanic<br>7 Unknown<br>3 Calling on behalf of others                                                                                                                                             | 21 Unknown                                                                                                                                                                                                                                                                                                                                                     |
| Form 2:<br>Source of Information<br>about the Clearinghouse<br><br>* denotes totals listed are for<br>the Clearinghouse in general | 1 Clearinghouse Brochure<br>3 Friend/Relative<br>12 Hospital<br>1 Information Line<br>4 Newspaper/Magazine<br>1 Pubic Agency<br>2 School<br>1 Self/Help Conference<br>1 Self/Help Group<br>10 Unknown | 1 Clearinghouse Brochure<br>2 Friend/Relative<br>3 Health Department<br>4 Hospital<br>1 Self/Help Group<br>1 Social Worker                                                                           | 23 Brochure<br>10 Directory<br>17 Newsletter<br>8 Clergy<br>9 Doctor<br>7 Emp. Ass.Prog<br>78 Friend/Rel.<br>2 Health Dept.<br>115 Hospital<br>26 Info. Line<br>15 Library<br>133 News./Mag.<br>9 Prev. Caller<br>53 Public Ag.<br>7 Radio<br>8 School<br>3 Self/Help Con.<br>47 Self/Help Gr.<br>2 Ph. Dir.<br>4 TV<br>159 Therapist<br>5 Unknown<br>7 Other* |
| Form 3:<br>Number & Nature of<br>new Support Groups                                                                                | None                                                                                                                                                                                                  | None                                                                                                                                                                                                 | Coping & Hoping,<br>Group for children with limb<br>deficiencies                                                                                                                                                                                                                                                                                               |
| Form 4:<br>Training & Technical<br>Assistance Provided                                                                             | None                                                                                                                                                                                                  | Assisted HIV Outreach to Youth;<br>Provided list of self-help groups to<br>Nassau County Planning Group;<br>Assisted Suffolk County Youth<br>Bureau in forming group for<br>children of Vietnam Vets | Sent Self-Help Packet<br>to group leader                                                                                                                                                                                                                                                                                                                       |
| Form 5:<br>Materials Disseminated                                                                                                  | None                                                                                                                                                                                                  | 300 Brochures<br>750 Newsletters<br>150 Flyers                                                                                                                                                       | None                                                                                                                                                                                                                                                                                                                                                           |
| Form 6:<br>Public Awareness Activities                                                                                             | None                                                                                                                                                                                                  | Radio: Ad for LI Chouse;<br>Print Media: Article in People<br>Helping People Newsletter                                                                                                              | None                                                                                                                                                                                                                                                                                                                                                           |

## Long Island

| Quarter                                                      | Oct. 1991-Jan. 1992                                                                                                                                                                        |                                                                                                                                                                             | January-April 1992                                                                                                                                                                               |                                                                                                                                                                                | April-July 1992                                                                                                                                                                                            |                                 |
|--------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
| Form 1:<br>Number &<br>Race of Callers                       | 24 Caucasian<br>7 Black<br>1 Hispanic                                                                                                                                                      |                                                                                                                                                                             | 16 Caucasian      1 Asian<br>3 Black            2 Other/Un.<br>3 Hispanic                                                                                                                        |                                                                                                                                                                                | 16 Caucasian      4 Other/Un.<br>4 Black            2 on behalf of<br>2 Hispanic        others                                                                                                             |                                 |
| Form 2:<br>Source of Information<br>about the Clearinghouse  | 3 Brochure<br>0 Directory<br>7 Newsletter<br>0 Poster<br>6 Clergy<br>7 Doctor<br>9 Emp. Ass. Prog.<br>51 Friend/Rel.<br>7 Health Dept.<br>58 Hospital<br>18 Info. Line<br>93 Social Worker | 16 Library<br>378 News/Mag.<br>6 Prev. Caller<br>62 Public Agen.<br>2 Radio<br>8 School<br>21 Self/Help Gr.<br>1 TV<br>1 Ph. Dir.<br>49 Therapist<br>8 Unknown<br>16 Other* | 20 Brochure<br>6 Directory<br>11 Newsletter<br>0 Poster<br>6 Clergy<br>4 Doctor<br>3 Emp. Ass. Prog.<br>115 Friend/Rel.<br>13 Health Dept.<br>102 Hospital<br>17 Info. Line<br>176 Social Wor.   | 4 Library<br>352 News/Mag.<br>16 Prev. Caller<br>89 Public Agen.<br>23 Radio<br>35 School<br>20 Self/Help Gr.<br>2 Ph. Dir.<br>0 TV<br>41 Therapist<br>11 Unknown<br>30 Other* | 1 Friend/Rel.<br>3 Health Dept.<br>1 Hospital<br>1 Info. Line<br>2 Library<br>4 Social Wor.<br>5 News/Mag.<br>1 Prev. Caller<br>1 Public Ag.<br>4 School<br>2 Self/Help Con.                               | 1 Self/Help<br>Group<br>2 Other |
| * denotes totals listed are for the Clearinghouse in general |                                                                                                                                                                                            |                                                                                                                                                                             |                                                                                                                                                                                                  |                                                                                                                                                                                |                                                                                                                                                                                                            |                                 |
| Form 3:<br>Number & Nature of<br>new Support Groups          | Continued aiding Coping & Hoping<br>and Limb Deficiencies Groups; Aided<br>Children w/ Facial Disfiguring Group                                                                            |                                                                                                                                                                             | Pediatric Sickle Cell Support Group;<br>Continued to aid group for children<br>with facial disfiguring                                                                                           |                                                                                                                                                                                | Cerebral Palsy support group for<br>parents; Network of caregivers for<br>children w/ Sickle Cell Disease                                                                                                  |                                 |
| Form 4:<br>Training & Technical<br>Assistance Provided       | In addition to above sent packets<br>to a group in formation for PKU<br>parents; Sent list of resources to group<br>facilitator for Sickle Cell Group                                      |                                                                                                                                                                             | Informed a group leader on<br>advertising a new support group                                                                                                                                    |                                                                                                                                                                                | Sent information to 2 potential group<br>leaders; Provided listing in People<br>Helping People of groups on L.I. for<br>teens & young adults                                                               |                                 |
| Form 5:<br>Materials Disseminated                            | 100 Brochure<br>1500 Newsletters                                                                                                                                                           |                                                                                                                                                                             | 5000 Newsletters<br>1000 Flyers                                                                                                                                                                  |                                                                                                                                                                                | 250 Brochures      600 Flyers<br>1000 Newsletters<br>12 Directories                                                                                                                                        |                                 |
| Form 6:<br>Public Awareness Activities                       | Presentations: PIH Exhibit at Resource<br>Fair;<br>Radio: Ads on 3 local stations;<br>Print Media: Sent news release to 25<br>local papers                                                 |                                                                                                                                                                             | Presentation: Health Fair at NYS<br>Institute of Technology; Radio: Ads<br>on local stations; Print Media: News<br>releases to 25 local papers; Other:<br>Ad in Women's Journal of AME<br>Church |                                                                                                                                                                                | Presentations: PIH Conference;<br>Empowering Families Con.; Radio:<br>Ad for PIH; Print Media: News<br>releases; Other: NYIT Health Fair;<br>African-Am. Issues con.; HIV<br>Outreach Committee open house |                                 |

## Long Island

| Quarter                                                     | July- October 1992                                                                                                                                                                         | Oct. 1992-Jan. 1993                                                                                                                                                                | Jan.-April 1993                                                                                                                                                                                                              |
|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number &<br>Race of Callers                      | 20 Caucasian      6 on behalf of<br>others<br>3 Black<br>1 Hispanic                                                                                                                        | 14 Caucasian      4 Asian<br>0 Black            25 Other<br>7 Hispanic                                                                                                             | 29 Caucasian      1 Greek<br>1 Black<br>8 Hispanic                                                                                                                                                                           |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 1 Brochure<br>2 Newsletter<br>3 Friend/Relative<br>3 Health Dept.<br>1 Hospital<br>6 Newspaper/Magazine<br>2 Previous Caller<br>3 Radio<br>1 School<br>2 Unknown<br>6 Social Worker        | 1 Clergy<br>1 Health Department<br>1 Hospital<br>1 Library<br>8 Newspaper/Magazine<br>9 Previous Caller<br>1 Unknown<br>4 Social Worker                                            | 1 Clearinghouse Poster<br>1 Doctor<br>4 Friend/Relative<br>3 Hospital<br>1 Information Line<br>2 Library<br>14 Newspaper/Magazine<br>1 Previous Caller<br>1 Public Agency<br>2 Self-Help Group<br>4 Unknown; 5 Social Worker |
| Form 3:<br>Number & Nature of<br>new Support Groups         | None                                                                                                                                                                                       | Parents of children with Fetal Alcohol<br>Syndrome; Parents of children with<br>Thalassemia and related blood<br>disorders                                                         | Children with handicaps through<br>LaUnion Hispanica                                                                                                                                                                         |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Aided facilitator in reaching new<br>members of Sickle Cell & CP group;<br>Provided general info. for 3 potential<br>group leaders; Helped parents link to<br>others with similar concerns | Helped reach potential members for<br>FAS, blood disorder & diabetes<br>group; Outreached to Hispanic<br>Community; Developed data base for<br>linking parents of similar concerns | Enhanced publicity for PIH in<br>Hispanic Community                                                                                                                                                                          |
| Form 5:<br>Materials Disseminated                           | 55 Brochures<br>1000 Newsletters<br>3 Self-Help Packets                                                                                                                                    | 200 Brochures      2 Self-Help<br>50 Newsletters      Packets<br>1000 Flyers                                                                                                       | 200 Brochures<br>25 Newsletters<br>1000 Flyers                                                                                                                                                                               |
| Form 6:<br>Public Awareness Activities                      | Radio: Public Service<br>Announcements;<br>Other: Articles in People Helping<br>People Newsletter                                                                                          | Presentation: St. Joseph's Church,<br>Babylon; Radio: Ads on local<br>stations; Print Media: News releases<br>to 25 local papers                                                   | Presentations: La Union Hispanica,<br>Brookhaven Spanish Apostolate,<br>Adelante of Suffolk County, Pronto of<br>LI; Radio: Public service<br>announcements; News releases                                                   |

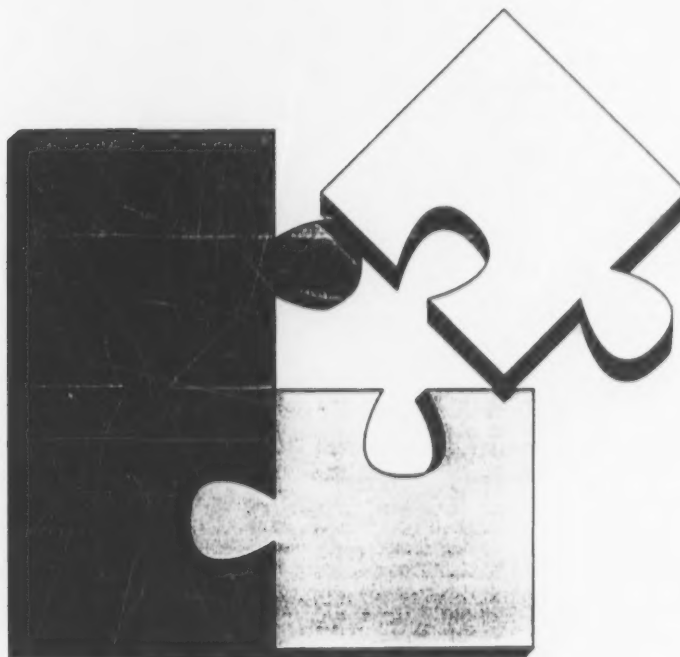
## Long Island

| Quarter                                                     | April-July 1993                                                                                                                        | July-October 1993                                                                                                                                                                                               |
|-------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Form 1:<br>Number &<br>Race of Callers                      | 29 Caucasian<br>18 Hispanic                                                                                                            | 35 Caucasian      1 Asian<br>3 Black<br>10 Hispanic                                                                                                                                                             |
| Form 2:<br>Source of Information<br>about the Clearinghouse | 2 Clergy<br>1 Hospital<br>2 Information Line<br>19 Newspaper/Magazine<br>14 Previous Caller<br>2 Public Agency<br>6 Unknown<br>1 Other | 4 Brochure      6 Previous Caller<br>1 Employee.      1 Public Agency<br>Assistance Prog.      1 Radio<br>2 Friend/Rel.      1 School<br>5 Hospital      1 Unknown<br>1 Info. Line<br>3 Library<br>20 News/Mag. |
| Form 3:<br>Number & Nature of<br>new Support Groups         | Worked towards forming the support<br>group for handicapped children with<br>La Union Hispanica, however future is<br>uncertain        | None                                                                                                                                                                                                            |
| Form 4:<br>Training & Technical<br>Assistance Provided      | Provided Information to BayShore,<br>Islip & Hispanic Communities;<br>Updated data base to link parents of<br>similar concerns         | Assisted group leader of Velo Cario<br>Facial Syndrome group leader;<br>Participated in mental health workshop;<br>Distribution of flyers at health fair & St.<br>Luke's Parish                                 |
| Form 5:<br>Materials Disseminated                           | 400 Brochures<br>25 Newsletters<br>1000 Flyers                                                                                         | 75 Brochures<br>600 Flyers                                                                                                                                                                                      |
| Form 6:<br>Public Awareness Activities                      | Presentations: Mental Health<br>Workshop/ NY Institute of<br>Technology;<br>Radio: Public service announcements                        | Presentations: Hempstead Hispanic<br>Counseling Center & St. Luke's Outreach<br>Center; Radio: Public service<br>announcements; News releases                                                                   |

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**Appendix 2**

**Evaluation Report  
Introductory Training Session  
Conducted June 10 and 11, 1991**



New York State Department of Health  
Bureau of Child and Adolescent Health



**EVALUATION REPORT**

**Introductory Training Session**

**Partners in Health:  
Self-Help/Mutual Support for Culturally Diverse Children  
with Special Health Needs and Their Families**

**Prepared by:**

**Mary Huber, Project Director  
Partners in Health  
New York State Department of Health  
Corning Tower, Room 765  
Empire State Plaza  
Albany, NY 12237**

**August 21, 1991**

The introductory training session was organized to meet three main objectives:

- o To provide both didactic and experiential learning on key topics: e.g., self-help/mutual support, engaging culturally diverse communities in mutual support.
- o To develop partnerships between case managers and self-help clearinghouses for work that will continue at local sites.
- o To provide information in a format that can be replicated at local sites.

By meeting the above objectives, the overall goal of the conference, to provide a framework for initiating "Partners in Health" at local sites, could be met.

#### TRAINING NEEDS:

The two-day conference was organized with the following needs in mind:

- 1) The primary audience for the session was staff of the Physically Handicapped Children's Program (PHCP) Case Management projects and self-help clearinghouses from the four demonstration sites - Albany, Nassau, Niagara and Suffolk counties.
- 2) Staff of the PHCP Case Management and self-help clearinghouses needed to learn about each other's disciplines and modes of operation.
- 3) Staff of PHCP and self-help clearinghouses needed to meet each other and develop a cooperative relationship to meet "Partners in Health" goals and objectives.
- 4) Sensitivity to issues of cultural diversity needed to be woven throughout the presentation. Although the project sites are working with many culturally diverse groups, neither time nor experienced speakers were available to address the range of needs. Consequently, the project director chose to feature information on African Americans, the largest cohort of culturally diverse residents in New York State and the group with which there is the most experience in developing mutual support activities.
- 5) It was necessary to give a special focus to the issue of community outreach, grass roots community organizing, public awareness to culturally diverse populations and other health communication strategies.

### CONFERENCE DESIGN:

In order to meet these needs, the training session was organized to encompass a variety of activities:

Formal presentations by speakers who had experiential and theoretical knowledge of subject areas;

Personal testimony by culturally diverse parents who have children with special health needs; and

Small work groups that would provide an opportunity for participants to apply knowledge learned to local "Partners in Health" activities.

### CHANGES MADE FROM ORIGINAL PROPOSAL:

As originally envisioned, all case management staff would attend the initial training session with expenses paid by the Department of Health Case Management contract. Due to budgetary restrictions, travel funds were not available. Consequently, only Albany County was able to support the attendance of all its case managers. Supervisory staff only attended from Nassau and Suffolk counties; supervisory staff and one of eight case managers attended from Niagara County.

With the absence of many case managers, local project staff were requested to replicate the training at local sites. To assist with this objective, many handouts were prepared that could be duplicated for local knowledge transfer.

### EVALUATION PROCESS:

In order to assess the extent to which goals and objectives were met, participants completed two types of evaluation.

1) Each session was rated individually on a scale of 1 (excellent) to 4 (poor) on four areas; program content, method of presentation, handouts, and overall evaluation of session. In addition to a numerical rating for each of these areas, participants were asked to comment on three areas: A) the best thing about each session; B) how the session could have been improved; and C) the relevance of the session to building partnerships between self-help and case management.

2) A summary evaluation of the conference in its entirety, which requested commentary on what should be done if this session were presented again; assessment of whether the session did or did not meet its objectives, the information participants will most be able to use, and any disappointments the session presented.

## EVALUATION RESULTS:

### **1. Individual Workshops**

The numerical rating of the overall evaluation for each session ranged from 1.25 to 1.78 with a mean of 1.5, the mid-range from good to excellent.

For additional information, please refer to the summary of each session's ratings, which are included at the end of the document.

As the attached summary sheets indicate, this high rating reflects participants' comments on the high quality of the speakers and the amount and high quality of information presented.

### PARTICIPANT EVALUATION TO OVERALL CONFERENCE:

Of the 17 participants who completed this evaluation, 16 indicated the training session did meet its objectives. One indicated that it both did and did not meet its objectives.

This participant thought that while the session provided an opportunity to meet the self-help staff, it did not result in the development of a partnership.

Suggestions for changes that should be made if this session were to be presented again, some of which are contradictory, are:

1. Include more parents and more members of culturally diverse populations;
2. Include more case managers;
3. Give information on other cultures besides African-Americans, such as Hispanics and migrants;
4. Provide more time for informal sessions;
5. Shorten the day and spend more time on topics;
6. Provide more breaks;
7. Bring in children with chronic illness and more culturally diverse families; and
8. Highlight DOH and other state agencies less and put more emphasis on self-help models and strategies to implement grant goals.

When asked to comment on which element of the conference participants would most be able to use, they listed the following:

1. The contact list (5 people);
2. Ideas for marketing and networking (5 people);
3. Confidence that project goals could be achieved; and
4. Insights from people of color.

When asked to comment on factors in the session that disappointed them, 12 participants provided no information. The following are substantive comments that were received:

1. County groups had insufficient time together; and
2. Lack of clarity regarding the relevant roles of self-help clearinghouses and case management in the project.

The latter comment must be given serious consideration because it addresses one of the primary purposes of the session. One of the reasons for the lack of clarity may be that the precise role of each organization is not yet cast in stone. While general guidelines for the relationship are outlined, the roles will become realized only through a developmental process of working together on various projects.

In addition to the above formal evaluation, the project director also received informal feedback from clearinghouses, a case management site, and a regional nurse, all of whom noted the training session was an excellent presentation.

In general, it is clear from participants' evaluation that the training session did meet its objectives. With the above comments in mind, the project director will make sure that culturally diverse families who have children with special health needs are represented at future sessions. Attempts will also be made to involve culturally diverse children with special health needs, and follow-up will be conducted with case management sites to assess their relationship to the project.

In addition, future training sessions will be developed in conjunction with the participants through a needs assessment.

### Session Evaluation

Session: Genesis of Partners in Health

Presenter(s): Mary Huber, Diana Denboba

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.65 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.73 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | 1.54 |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.76 |
| 5. The best thing about this session was: |           |      |      |      |      |

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6. This session could have been improved by:

Visual aid

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7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

Helped familiarize one with appropriate attitudes and terminology to communicate adequately and effectively with others

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Thank you for taking the time to evaluate this session.



## Session Evaluation

Session: Children with Special Health Care Need and Their Families

Presenter(s): Nancy Kehoe, Wendy Shaw

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.55 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.65 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | 1.83 |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.47 |
| 5. The best thing about this session was: |           |      |      |      |      |

- (1) Even though Wendy claims public speaking is not her forte, she was very good.
- (2) Very informed speakers
- (3) Important information on case management

6. This session could have been improved by:

- (1) Some visuals

7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

- (1) Good overhead information

Thank you for taking the time to evaluate this session.

## Session Evaluation

Session Panel Presentation by Parents of Children with Special Health Needs  
 Presenter(s): Paul Martin, Cheryl Cannon, Janet Foster

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.24 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.2  |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | NA   |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.25 |
| 5. The best thing about this session was: |           |      |      |      |      |

The honesty in the telling of their stories was truly inspiring.

6. This session could have been improved by:

(1) Would like to hear from chronically ill children also, and from even more parents.

(2) More time.

7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

(1) Gave excellent validation that parents can benefit greatly from these groups.

(2) Family may not be ready for us initially.

Thank you for taking the time to evaluate this session.

## Session Evaluation

Session: Roles for Professionals in Self-Help

Presenter(s): Leslie Jameson

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.38 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.33 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | NA   |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.40 |
| 5. The best thing about this session was: |           |      |      |      |      |

(1) Speaker shared wealth of information and experiences in a down-to-earth way

6. This session could have been improved by:

(1) More time

(2) Might have been helpful to have a case manager discuss his/her role

7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

(1) Grass roots information was excellent . Good constructive advice.

(2) Step back and be less assertive

(3) This should be published

Thank you for taking the time to evaluate this session.

### Session Evaluation

Session: Engaging Culturally Diverse Communities in Self-Help

Presenter(s): Kenneth Cunningham

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.3  |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.27 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | NA   |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.32 |
| 5. The best thing about this session was: |           |      |      |      |      |

- (1) Practical information
- (2) Great sense of humor
- (3) Lively and informative
- (4) Great presentation

6. This session could have been improved by:

- (1) More time
- (2) Would have liked handouts

7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

- (1) Suggestion to have a liaison person from black - hispanic community to accompany you in making contacts

Thank you for taking the time to evaluate this session.

### Session Evaluation

Session: Outreach to Culturally Diverse Communities: Part I

Presenter(s): Catherine McHugh, Loretta Goff, Lisa Grippo-Gardner

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                  | Excellent | Good | Fair | Poor | Mean |
|----------------------------------|-----------|------|------|------|------|
| 1. Program Content               | 1         | 2    | 3    | 4    | 1.7  |
| 2. Method of Presentation        | 1         | 2    | 3    | 4    | 1.76 |
| 3. Handouts (if applicable)      | 1         | 2    | 3    | 4    | 1.38 |
| 4. Overall evaluation of session | 1         | 2    | 3    | 4    | 1.7  |

5. The best thing about this session was:

- (1) Speakers provided lots of information along with creative approaches and ideas, especially marketing and outreach.
- (2) Some good ideas on marketing use management

6. This session could have been improved by:

7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

- (1) Tips on pamphlets and flyers very useful

Thank you for taking the time to evaluate this session.

## Session Evaluation

Session: Outreach to Culturally Diverse Communities: Part 2

Presenter(s): Lovette Korhone

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.23 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 1.14 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    | NA   |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.23 |
| 5. The best thing about this session was: |           |      |      |      |      |

Grass roots content, practical information, delightful style,  
sense of humor.

6. This session could have been improved by:

7. Please comment on and describe the relevance of this session  
on building partnerships between self-help and case management  
in your community.

(1) She gave insight into what a black, poor woman faces in a white,  
middle class self-help group.

(2) Shows need to connect with other agencies and services

Thank you for taking the time to evaluate this session.



### Session Evaluation

Session: Small Workgroups on Monday and Tuesday

Presenter(s): Participants of Conference

Please rate each of the following:

This session was: Excellent - Good - Fair - Poor

|                                           | Excellent | Good | Fair | Poor | Mean |
|-------------------------------------------|-----------|------|------|------|------|
| 1. Program Content                        | 1         | 2    | 3    | 4    | 1.88 |
| 2. Method of Presentation                 | 1         | 2    | 3    | 4    | 2.13 |
| 3. Handouts (if applicable)               | 1         | 2    | 3    | 4    |      |
| 4. Overall evaluation of session          | 1         | 2    | 3    | 4    | 1.78 |
| 5. The best thing about this session was: |           |      |      |      |      |

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6. This session could have been improved by:

(1) Needed more time

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7. Please comment on and describe the relevance of this session on building partnerships between self-help and case management in your community.

(1) Will plan future meetings. This made all aware of vastness of objectives

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Thank you for taking the time to evaluate this session.

## Introductory Training Session

### Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families

#### Agenda

#### Objectives:

- o To provide both didactic and experiential learning on key topics: e.g., self-help/mutual support, engaging culturally diverse communities in mutual support.
- o To develop partnerships between case managers and self-help clearinghouses for work that will continue at local sites.
- o To provide information in a format that can be replicated at local sites.

#### Expected Outcome:

The establishment of a framework for developing Partners in Health activities among implementors at local sites.

#### DAY 1

10:30 am to 11:30 am      Welcome: Monica Meyer, M.D., Director  
Division of Family Health, NYSDOH

- o Introductory Exercise
- o Genesis of Partners in Health      Mary Huber, Project Director
  - Overview of Self-Help/Mutual Support in New York State
  - Development and Role of Self-Help Clearinghouses
  - Federal Initiative of Family Centered, Community Based, Coordinated Care for Children with Special Health Needs and Their Families      Diana Denboba, Policy Analyst  
USDHHS, Maternal and Child Health Bureau

11:30 am to 12:30 pm

Self-Help/Mutual Support for Children with Special Health Needs and Their Families as a Culturally Competent System of Care. Families who participate in self-help/mutual support will discuss their experiences. Cheryl Cannon, Sickie Cell Support Group; Paul Martin, Telephone Network.

12:30 pm to 1:15 pm      Lunch

1:15 pm to 1:30 pm

Comments from Linda Randolph, MD, MPH, Director, Office of Public Health, NYS Department of Health, Principal Investigator, Partners in Health

1:30 pm to 2:00 pm

Self-Help/Mutual Support: Ethos, Methodology, Models, and Networks.  
MaryHuber

2:00 pm to 2:30 pm

Roles for Health Professionals in Self-Help: How to Encourage the Movement While Maintaining Its Autonomy. Leslie Jameson, PhD, Director, Westchester Self-Help Clearinghouse

2:30 pm to 3:00 pm

Engaging Culturally Diverse Communities in Self-Help: One Community's Experience. Kenneth Cunningham, Founder and President, Positive Renal Outreach Program

3:00 to 3:30 pm

Partners in Health Workplan: Signposts and Milestones. Mary Huber

3:30 pm to 4:00 pm

Work groups by county. In small groups, participants will brainstorm resources, potential barriers, problems and solutions for implementing Partners in Health in each locale.

4:00 pm to 4:30 pm

Work groups report to general session.

4:30 pm to 5:00 pm

Review of the day. Preview of Day 2. Evaluation.

## DAY 2

8:30 am to 9:15 am

For self-help clearinghouse staff only, this session will provide information on administrative procedures as subcontractors.

9:15 am to 9:30 am Review of previous day's proceedings.

9:30 am to 10:00 am

Children with Special Health Care Needs and Their Families:

Prevalence, Characteristics, and Needs and New York State's Physically Handicapped Children's Program and Case Management Program. Nancy Kehoe, Director, Physically Handicapped Children's Program and Wendy Shaw, Maternal and Child Health Consultant Nurse

10:00 am to 11:00 am

Outreach to Culturally Diverse Communities: Part 1

Presentation by staff of the NYS Commission on Quality of Care for the Mentally Disabled Minority Outreach Project. Catharine McHugh, Advocacy Training Coordinator, Loretta Goff, Minority Outreach Coordinator, and Lisa Grippo-Gardner, Education and Training Coordinator, Catholic Charities

11:00 am to 11:45 am

Outreach to Culturally Diverse Communities: Part 2

Presentation by Lovette Korhone, Community Health Worker, Albany County Department of Health

11:45 am to 12:15 am

Presentation on Related Initiatives in NYS Department of Health.

Donna Noyes, PhD, Assistant Director, Early Intervention Program and Dan Burrows, NYS Sickle Cell Services Coordinator

12:15 pm to 1:15 pm Lunch

1:15 pm to 2:00 pm

Small Group Work on Two Issues:

- o Identifying indigenous leaders, natural helpers, project allies
- o Identifying outreach efforts to culturally diverse communities

2:00 pm to 2:15 pm

Wrap-up and Conclusion

2:15 pm to 2:30

Evaluation of Conference

This conference is supported in part by Project #MCJ367034010 from the Maternal and Child Health Program (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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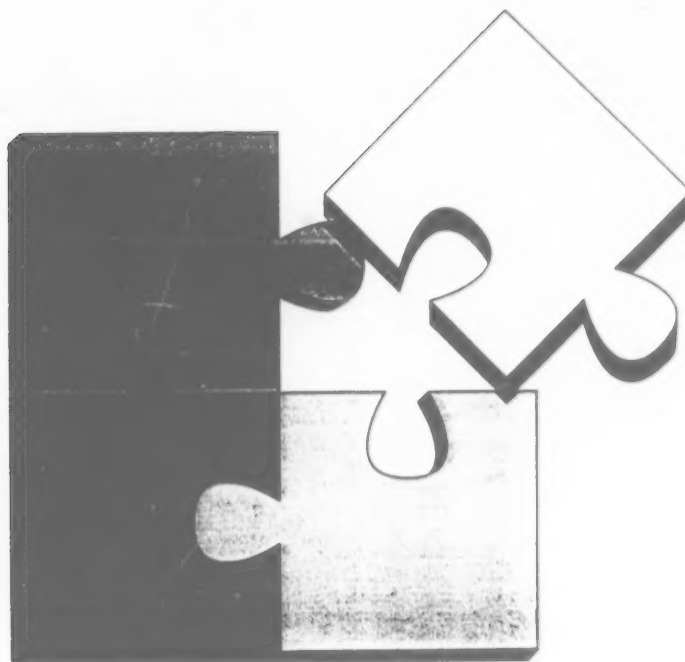
## **Appendix 3**

### ***Evaluation Report Training Sessions***

# **Developing Culturally Competent Programs for Children with Special Needs**

**Part 1**

**January 3, 1992**



**New York State Department of Health  
Bureau of Child and Adolescent Health**

## **EVALUATION REPORT**

### **Training Sessions**

**Developing Culturally Competent Programs  
for Children with Special Health Needs**

#### **Part 1**

**Prepared by:  
Mary Huber, Project Director  
Partners in Health**

**January 3, 1992**

**New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208 Corning Tower Building  
Empire State Plaza  
Albany, NY 12237**



This project is supported in part by Project #MCJ367034010 from  
the Maternal and Child Health Program  
(Title V, Social Security Act),  
Health Resources and Services Administration,  
Department of Health and Human Services

## INTRODUCTION

This *Evaluation Report* documents the planning, delivery, and follow-up activities for a training series that the New York State Department of Health, Bureau of Child and Adolescent Health, undertook to increase the cultural competence of its Children with Special Health Care Needs services system. Topics in this report include: training content, objectives, techniques, evaluation, follow-up activities, and a bibliography.

The sessions were conducted as part of the work plan for the Federal Maternal and Child Health Bureau (MCHB) SPRANS grant, **Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families (PIH)**. Entitled **Developing Culturally Competent Programs for Children with Special Health Needs**, the programs were conducted in three sites across the state. Participants were staff of the 12 case management programs operated by the Physically Handicapped Children's Program (PHCP), the state's Title V Children with Special Health Care Needs program, and staff from the three self-help clearinghouses that comprise the Partners in Health demonstration sites.

The purpose of case management is to assist families to coordinate a wide range of services and programs families may find useful in caring for their children with special health needs. Self-help clearinghouses link families to informal supports, other families who are also caring for children with special health needs.

Meeting sites and dates were:

|               |                    |
|---------------|--------------------|
| Niagara Falls | September 10, 1991 |
| Albany        | September 12, 1991 |
| Hauppauge     | September 13, 1991 |

## NEED FOR THE TRAINING

The need for the sessions flowed from the recent Title V mandates that call for maternal and child health services that are family centered, community based, culturally competent, and effectively coordinated. The definition used to guide the development of culturally competence services is taken from the

monograph, *Developing Culturally Competent Programs for Families of Children with Special Health Needs* (Roberts, et al., 1990). As defined in that publication, "cultural competence refers to a program's ability to honor and respect those beliefs, interpersonal styles, attitudes and behaviors both of families who are clients and the multicultural staff who are providing policy, administration and practice (p. 4)."

In fulfillment of this mandate, in 1990 New York State's PHCP developed a number of objectives to improve services to children who are culturally diverse. New York State's plan contains the following goal and objectives:

Goal: Implement 12 pilot projects in New York State that provide family centered, community based case management services that are culturally sensitive and culturally competent.

Objectives:

1. Develop a clear policy statement of the need for culturally competent programs.
2. Disseminate policy statement to county projects.
3. Ask projects to identify culturally diverse populations within catchment areas.
4. Ask projects to identify a particular cultural group and provide special outreach services to them.
5. Build in the need for cultural diversity/sensitivity in staff job qualifications; assist counties in developing culturally competent job descriptions.
6. Train current staff in cultural sensitivity.
7. Assist in recruiting culturally diverse staff.

In addition to fulfilling some of the above objectives, the sessions were also designed to fulfill the training needs outlined in PIH.

## THE CHALLENGE OF PROVIDING TRAINING IN CULTURAL COMPETENCY

Previous training on cultural competency had been provided in this first training session administered by **Partners in Health**. This effort focused on outreach strategies to culturally diverse families, particularly as it related to engaging them in self-help/mutual support networks. Only the four case management projects involved in **Partners in Health** participated. While this session was a helpful starting point, it was necessary to provide training on cultural competency for all case management sites and to broaden the focus to include case management services.

The concept of cultural competency in the field of health services delivery is relatively recent. The application of cultural competency to the field of children with special health needs is even more recent. Training on this subject had never been presented in the state. Given this background, the goals of the training were: 1) to create a general awareness of cultural competency; and 2) to translate that awareness into program practice.

### SPEAKERS

The task of identifying speakers who have both theoretical and experiential knowledge of the field of delivering culturally competent services to children with special health needs was difficult. Fortunately, two such speakers were identified through the MCHB Work Group on Cultural Competency. The Work Group is an ad hoc advisory group to the MCH Bureau whose purpose is to consider issues of planning systems, programs, and technical assistance related to serving culturally diverse populations. Both have played a leadership role within that group and participated in the development of the monograph mentioned above.

Richard Roberts, Ph.D., is co-director of the Early Intervention Research Institute of Utah State University where he directs the research and evaluation components of the Developmental Center for Handicapped Persons. He is the former chairperson of the MCHB Work Group on Cultural Competency. Among other experiences, his knowledge of cultural competency is grounded in his activities developing early intervention programs among native Hawaiians and among American Indians in the western United States.

Currently a Ph.D. candidate at the University of Michigan, Ms. Gina Barclay-McLaughlin recently developed a model early intervention program at the Robert Taylor Homes, in Chicago, Illinois, the oldest and largest public housing project in the country. Over the last 20 years she has traveled extensively nationally and internationally to study the impact of culture on child rearing. She, too, is a member of the MCHB Work Group on Cultural Competency

As will be shown in the summary of participants' evaluations, both made important contributions to the positive outcome of the training.

### PARTICIPANTS

The grant was designed to provide training on cultural competency for the four case management projects and three self-help clearinghouses that constitute the demonstration sites for PIH. However, PIH funds provided the perfect opportunity to extend the audience from the demonstration sites to all case management sites statewide. In addition to case management staff, participants included two culturally diverse parents of children with special health needs, and central and regional staff with responsibilities to the PHCP programs from the NYS Department of Health. In Niagara County, eight of the co-case managers are parents of children with special needs. They are counted in the category of staff, although their dual role should be noted.

#### Number of Attendees:

| Case Management Staff | Self-Help Clearinghouse Staff |
|-----------------------|-------------------------------|
| 31                    | 12                            |
| DOH Staff             | Parents                       |
| 14                    | 2                             |

Total Participants = 59

### Ethnicity of Attendees

As part of the evaluation, participants were invited to indicate their ethnocultural background. Of those who responded (54 of 59 participants, 92%), the following identification was given:

43 White      8 Black      3 Native American

### BEHAVIORAL OBJECTIVES OF TRAINING

Content for the training derived from two publications, *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (Cross, et al., 1989), and *Developing Culturally Competent Programs for Families of Children with Special Health Needs* (Roberts, et al., 1990).

Discussions among PHCP administrative staff, the project director, and the trainers resulted in establishing the following behavioral objectives and key content areas.

Participants will be able to:

1. Define a culturally competent system of care.
2. Describe the continuum of cultural competence from cultural destructiveness to cultural competence.
3. Describe the relationship between cultural competence and family centered, community based, coordinated care.
4. Provide at least one example of culturally competent care in each of the areas of policy, training and practice.
5. Describe the difference between models of intervention that use cultural stereotyping and ones that are truly culturally competent.
6. Relate the principles of culturally competent practice to one area of their own professional practice with a plan for intervention.



## APPROACH

The presenters used a variety of methods to present the material: lecture, discussion between the presenters and between the presenters and the participants, and small group work. As a culminating activity, participants began the process of developing culturally competent programs for their local sites in one area -- policy, training, assessment, or outreach.

In addition, each participant received a copy of the monograph, *Developing Culturally Competent Programs for Families of Children with Special Health Needs* and its workbook for reference and continued study at local sites. Each site also received a copy of *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (Cross, et al., 1989), which provides information on the cultural competence continuum. A bibliography on cultural competency completed the information packet.

In order to reinforce the material discussed at the workshop, each of the case management sites submitted to the central office a goal and objective related to cultural competency as part of their work plan for the upcoming contract year.

## PARTICIPANT EVALUATIONS

The following section summarizes the evaluation forms completed by participants.

### Overall Rating

Participants rated several categories with a numerical score that ranged from one for excellent to four for poor. Thus, scores closest to one are most favorable. They are reported here on an individual and aggregate site basis.

| Niagara Falls             | Mean Score | Range |
|---------------------------|------------|-------|
| 1. Program Content        | 2          | 1 - 3 |
| 2. Method of Presentation | 1.7        | 1 - 3 |
| 3. Handouts               | 1.6        | 1 - 3 |
| 4. Overall Evaluation     | 1.8        | 1 - 3 |

| Albany                    | Mean Score | Range |
|---------------------------|------------|-------|
| 1. Program Content        | 1.3        | 1 - 2 |
| 2. Method of Presentation | 1.2        | 1 - 3 |
| 3. Handouts               | 1.3        | 1 - 2 |
| 4. Overall Evaluation     | 1.3        | 1 - 2 |
| Hauppauge                 | Mean Score | Range |
| 1. Program Content        | 1.2        | 1 - 2 |
| 2. Method of Presentation | 1.2        | 1 - 2 |
| 3. Handouts               | 1.2        | 1 - 2 |
| 4. Overall Evaluation     | 1.3        | 1 - 2 |
| Average of Three Sites    | Mean Score |       |
| 1. Program Content        | 1.5        |       |
| 2. Method of Presentation | 1.4        |       |
| 3. Handouts               | 1.4        |       |
| 4. Overall Evaluation     | 1.5        |       |

The somewhat lower evaluation from the presentation in Niagara Falls may reflect the fact that it was the first session and therefore a testing ground for seeing how the day would go. Based on the participants' evaluations and comments, the trainers tightened up the day for the next two sessions by eliminating an opening exercise and devoting more time to group work at the end.

In addition to rating the conference with a numerical score, participants also responded to a series of open-ended questions. Responses are summarized below.

#### **Best thing about the session:**

The most frequent response to this question affirmed the combination of lecture and audience interaction that the speakers used to present their material. Participants also appreciated the presenters' teamwork and rich range of experiences that clarified the theoretical principles of cultural competency.

### **Ways session could have been improved:**

The majority of respondents did not supply information on this topic. Three mentioned that they would like more time on the topic and three mentioned that they would like specificity on particular cultural groups. It should be noted that the presenters made a conscious decision not to supply such information and cautioned participants about the cultural stereotyping that can result when, for example, Hispanics are categorized as thinking one way or American Indians another. Two respondents thought the content was too basic.

### **Did you learn of methods for developing culturally competent programs that are needed or missing in your program?**

Thirty-nine participants replied yes, eleven replied no.

Many respondents cited examples of these methods, which cover a broad range of items, and, in fact, do reflect that the goals and objectives of the session were achieved. Items cited are:

- considering ways to reach ethnic groups;
- need to consider staffing patterns;
- seeking out people of different cultures to help programs create a policy on cultural competency;
- patience in learning specifics of particular cultures;
- innovation in designing programs to meet the need;
- greater awareness of cultural diversity in assessment of child and family;
- developing a policy on cultural competency;
- engaging culturally diverse people as volunteers; and
- need for more staff training.

**Based on this session, are there applications of culturally competent practice that you intend to use in your professional practice?**

42 yes

3 no

In response to this question, respondents listed many of the items cited in the previous response, although there was some degree of greater specificity. Practices include:

- work with Amish community
- educate co-workers and administrators on cultural competency;
- consider composition of quality assurance team; and
- use workbook to develop future plans.

#### **Obstacles to implementing:**

Only two participants responded to this question. This low number is probably a function of lack of time to respond to the question thoughtfully rather than a lack of obstacles. One participant noted the difficulty of having parents on advisory boards due to their work schedules and transportation difficulties.

#### **General comments:**

Many participants took the opportunity to respond to an open-ended question that invited comments on the session. Typical of the responses are the following:

- "Experiences like today will have to be made available to many people at many times before American society is profoundly changed. Good beginning for these projects."
- "Wonderful day with many thoughts to feast on!"
- "Extremely informative"
- "Applicable to a wide range of cultures."
- "Would like more information about bringing about change in this society. One-on-one relationships are not sufficient."
- "Entire human services system needs this training."
- "Excellent. Well spent time."
- "A big thank you to Richard and Gina."

#### **NEXT STEPS**

As a follow-up to the need to learn more about specific cultures, case management programs in western New York State, which serve several American Indian communities, invited an American Indian to a regional case management forum. At the forum, the speaker described several important elements of American Indian traditions.

Additional follow-up to the conferences will be provided through one or more of the following methods:

1. **Partners in Health** will sponsor additional training session. If possible, Richard Roberts and Gina Barclay-McLaughlin will return to provide assistance to case management projects on implementing their cultural competency work plans. (See examples below.)
2. PHCP central office staff will monitor implementation of cultural competency work plans by reviewing quarterly and annual reports and providing technical assistance.
3. **Partners in Health** will develop technical assistance materials in working with culturally diverse populations and distribute them to case management sites.

Following is a record of the cultural competency objectives developed by the case management sites and received in the central office as of January 3, 1992.

#### **Erie County**

Objective: To heighten awareness of the PHC Case Management Program among culturally diverse populations.

| <u>Activity</u>                                                                                                                                                 | <u>Measure</u>               | <u>Completed</u>                     |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|--------------------------------------|
| A. Program staff will develop a list of local persons and/or agencies that will provide translation services, as required, for the PHC Case Management Program. | List of persons agencies     | November, 1991                       |
| B. Program will have written materials (brochures, forms, letters, etc.) translated into Spanish.                                                               | Number of pieces translated. | Six pieces to be translated by June, |

C. Program staff will distribute 850 pieces of translated literature to Hispanic families and agencies.

Number of pieces distributed

January through September, 1992

Activity

Measure

Completed

D. Case Management staff will visit a total of 30 agencies that serve culturally diverse children with special needs in order to provide information on the PHC Case Management Program, and to learn about community resources.

Number of agencies

October, 1992

**Essex County:**

Although Essex County lacks a specific culturally diverse population, there are many families who are economically disadvantaged and living in an isolated rural setting. With the goal of promoting cultural competence, the following objectives have been established.

**1. Outreach and Public Awareness**

To facilitate increased awareness and improve access to services, presentation will be given to providers of children's services who work closely with the target population. Providers will include Head Start, Early Childhood Intervention, Committee for Preschool Education, Medicaid case workers, CHAP, children's services/DSS, and CHANCE (interagency group of children's services providers who meet five times a year for information sharing and networking).

**2. In-service Training**

A one-day in-service training will be provided by NYSDOH Regional Nurse and parent of handicapped child to orient maternal child health staff to the philosophy and practice of a culturally sensitive family-centered approach to case management.



### 3. Assessment

The Family Services Assessment for Case Management Services will incorporate a section on culturally sensitive issues and practices for each family.

#### **Herkimer County:**

Objective: Penetrate the Herkimer County Amish community

Activity:

1. Identify 'spokesperson' for Amish community;
2. Two-way education, exchange of information, become familiar with the Amish culture;
3. Offer "public health services" as a whole (PCAP, Well-Child and Immunization Clinics, PHCP, etc.) and perhaps utilize a "barter" system (i.e., building a ramp for a child on PHCP) if they will not accept public health's free services; and
4. Reintroduce ourselves to the town general practitioner and his staff.

#### **Nassau County:**

Objective: Increase the number of families served by intensifying outreach efforts.

| <u>Activity</u>                                                                                       | <u>Measure</u>                                                       | <u>Completed</u>      |
|-------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------|-----------------------|
| Develop an outreach program culturally sensitive to minority children with special health care needs. | Translate Case Management Program brochure into Spanish.             | Complete by 12/15/91. |
|                                                                                                       | Translate all case management forms used with families into Spanish. | Complete by 1/15/92.  |

|                                                                                                                                                                                           |                                                                                                                               |                         |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-------------------------|
|                                                                                                                                                                                           | Hire a full time<br>bilingual case<br>manager.                                                                                | In place                |
| Target six communities<br>identified by 1990<br>census as having a high<br>percentage of<br>African-American and<br>Hispanic residents and<br>introduce an intensive<br>outreach program. | Work collabora-<br>tively with<br>Partners in Health<br>Program to coordinate<br>outreach efforts in<br>target communities.   | Initiate by<br>12/1/91. |
|                                                                                                                                                                                           | Identify contact<br>person in local<br>clergy to serve as<br>liaison to various<br>congregations and<br>parish organizations. | Initiate by<br>12/1/91  |

#### Niagara County:

Objective: Increase public awareness to culturally diverse and underserved population.

| <u>Activity</u>                                                                                                                                                         | <u>Measure</u>                                                                                    | <u>Completed</u>                       |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|----------------------------------------|
| Contact PTA<br>Chairpersons to<br>obtain permission<br>to speak to and<br>disseminate Case<br>Management<br>Information in target<br>areas.                             | Increase in Case<br>Management referrals<br>from culturally<br>diverse/underserved<br>populations | October, 1991<br>through<br>June, 1992 |
| Approach clergy in<br>target areas, discuss<br>case management services<br>(CMS) availability and<br>request permission to<br>include CMS flyers in<br>weekly bulletin. | "                                                                                                 | October, 1991 -<br>ongoing             |

Objective: Have Case Management flyers included in mailings or handouts by Social Services, including Child Welfare/Child Abuse Division

| <u>Activity</u>                                                                                                                                                                                                 | <u>Measure</u>                                                                        | <u>Completed</u> |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|------------------|
| Write to Niagara County Commissioner of Social Services for permission to have CMS flyers either included in mailings or be available for handouts by his staff. Including Child Welfare/Child Abuse Divisions. | Increase in Case Management referrals from culturally diverse/underserved populations | October, 1991    |

Objective: CMS flyer will be included in WIC mailings.

| <u>Activity</u>                                                          | <u>Measure</u> | <u>Completed</u> |
|--------------------------------------------------------------------------|----------------|------------------|
| WIC Administrator will be asked to include CMS flyer in monthly mailings | "              | November, 1991   |

Objective: Assist Mental Health of Niagara County Self-Help Clearinghouse with their Partners in Health Grant.

| <u>Activity</u>                                                                                                                                                            | <u>Measure</u>                            | <u>Completed</u> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|------------------|
| Refer and receive referrals of Native Americans, black, migrant population with special health are needs. Establish support groups. Have in service on cultural diversity. | Referrals made and CMS receives referrals | ongoing          |

## Onondaga County:

Objective: To continue aggressive outreach activities with culturally diverse populations.

| <u>Activity</u>                                                                                                              | <u>Measure</u> | <u>Completed</u>                                          |
|------------------------------------------------------------------------------------------------------------------------------|----------------|-----------------------------------------------------------|
| Case Managers will attend WIC and well child clinics to personally explain Case Management to eligible families.             |                | October and November on trial basis & monthly thereafter. |
| Contact public school nurses and guidance counselors in all county schools.                                                  |                |                                                           |
| Continue to meet with Infant Health Assessment Program (IHAP) nurses.                                                        |                | Bi-monthly                                                |
| Visit at least one other agency, support group, etc. in addition to continued telephone and mail contacts with these groups. |                | Monthly                                                   |

## Orleans County:

Orleans County, a rural local in upstate New York, selected as its culturally diverse population families who are poor; a proportion of this population is minority. In addition to contacting traditional minority representatives (ministerial) begun in 90-91, program representative will arrange a presentation to area community based organization staff which traditionally serve minority and low-income groups. Previous contacts have been made with the Rural New York Farmworker Organization and the Migrant Children's Program to familiarize them with the program.

**Suffolk County:**

**Objective:** Increase outreach to Hispanic Community in catchment Area A.

| <u>Activity</u>                                                                                                                                                                                                                                        | <u>Measure</u> | <u>Completed</u>              |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|-------------------------------|
| Case Manager to consult with social worker at Coram Health Center, outreach workers at South Brookhaven Health Center and organization "La Vita Christiano" in Patchogue to plan and develop outreach to Hispanic community in the town of Brookhaven. |                | January, 1992                 |
| Case Managers will explore different types of support groups and select and develop those most appropriate for families they are involved with. Utilize staff and literature of "Partners in Health."                                                  |                | ASAP and throughout the year. |

**Tompkins County:**

**Objective:** To make Case Management Project more culturally competent.

### Activity

Purchase and review at least one resource (book, monograph, etc.) pertaining to cultural competence service delivery.

Utilize Ecomap to identify resources available to the family within their biological family and community.

With initial contact, get acquainted with the family, build rapport, have no set, rigid agenda.

Involve extended family and/or support network.

Ask questions concerning culture when unfamiliar with the family's culture.

Keep an open mind and be aware of own values--service plan will reflect the family's goals.

### **Yates County:**

Objective: To be incorporated during the first and second quarters (October 1, 1991 to March 31, 1992) in order to achieve cultural competency in dealing with the Mennonite community.

### Activity

A policy statement will be incorporated for the Physically Handicapped Children's Program which will reflect our commitment to develop a more culturally competent program. This will be reflected in our pamphlet as well as the Policy and Procedure Manual.

A determination of a number of Mennonite families in Yates County will be made in an effort to determine the number of children that would need to be served.

Interaction with one to two Mennonite families presently enrolled in the program in an effort to learn more about their culture (i.e., beliefs, medical practice, religion, and customs.)



Outreach efforts will be directed toward the midwives who deliver most of the Mennonite babies and family members who already utilize the program (so that that they will outreach to other families) and church leader(s).

Not available:

Albany County  
New York City

## Session Evaluation

Developing Culturally Competent Programs for Children with Special  
Health Needs September 1991

Please rate each of the following:

|                                  | Excellent | Good | Fair | Poor |
|----------------------------------|-----------|------|------|------|
| 1. Program Content               | 1         | 2    | 3    | 4    |
| 2. Method of Presentation        | 1         | 2    | 3    | 4    |
| 3. Handouts                      | 1         | 2    | 3    | 4    |
| 4. Overall evaluation of session | 1         | 2    | 3    | 4    |

5. The best thing about this session was:

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6. This session could have been improved by:

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7. Did you learn of methods of developing culturally competent  
programs that are needed or missing in your program?

\_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, list specific examples:

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8. Based on this session, are there applications of culturally competent practice that you intend to use in your professional practice? \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, please list specific practices?

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If no, list specific obstacles to implementation:

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9. Please use this space for other comments you would like to make about this training session in cultural competency.

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**Survey of Session Participants' Ethnocultural Background**  
The Maternal and Child Health Bureau, USDHHS, has requested that we collect the following data. This information is for statistical purposes only and is purely voluntary. Check as appropriate.

|                      |             |                       |
|----------------------|-------------|-----------------------|
| _____ White          | _____ Black | _____ Black Hispanic  |
| _____ White Hispanic | _____ Asian | _____ Native American |
| _____ Other          |             |                       |

**Thank you for taking the time to evaluate this session.**

## BIBLIOGRAPHY

### DEVELOPING CULTURALLY COMPETENT PROGRAMS

Cross, T., Bazron, B., Dennis, K., and Isaacs, M., *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, CAASP Technical Assistance Center, Georgetown University Child Development Center, Washington, DC, 1989. Although this monograph focuses on the issue of emotional disturbance, it provides a philosophical framework and practical ideas for improving service delivery to children of color for all issues.

Available from: CAASP Technical Assistance Center  
Georgetown University Child Development Center  
3800 Reservoir Road, NW  
Washington, DC 20007  
(202) 687-8635

Price: \$ 8.00 plus shipping and handling

Malach, R., Segel, N., and Thomas, T., *Overcoming Obstacles and Improving Outcomes: Early Intervention Services for Indian Children with Special Needs*, Southwest Communication Resources, Bernalillo, New Mexico, 1989. This publication identifies and discusses some important issues that must be considered when providing early intervention services to American Indian infants and their families. The focus is on issues related to the cultural differences between Indians and non-Indians and how this affects the provision of early intervention services.

Available from: Southwest Communication Resources  
PO Box 788  
Bernalillo, NM 37004  
(505) 867-3396

Price: \$10.00 plus 10% postage/handling

National Center for Youth and Disabilities, *Race and Ethnicity: Issues for Adolescents with Chronic Illnesses and Disabilities*, National Center for Youth and Disabilities, 1991. Examines health, education, and vocational issues as well as general psychosocial issues for adolescents and parents from various ethnic and racial groups.

Available from: National Center for Youth with Disabilities  
Box 7212 UMHC  
Harvard Street at East River Road  
Minneapolis, MN 55455  
(800) 333-6293

Price: \$3.50

Roberts, et al., *Developing Culturally Competent Programs for Children with Special Needs*, Georgetown University Child Development Center, Washington, DC, 1990. (Monograph) Discusses general issues in developing culturally competent services in relationship to community-based family-centered care and specific issues of policy and practice related to culturally competent services. Presents models of existing programs that are culturally competent.

Available from: CAASP  
(see above)

Price: \$4.00

Roberts, et al., *Workbook for Developing Culturally Competent Programs for Children with Special Needs*, Georgetown University Child Development Center, Washington, DC, 1990. (Workbook) Designed to accompany the above monograph, the workbook provides a means for programs to examine their policies and practices and to target areas where cultural competence can be improved.

Available from: CAASP  
(see above)

Price: \$4.00

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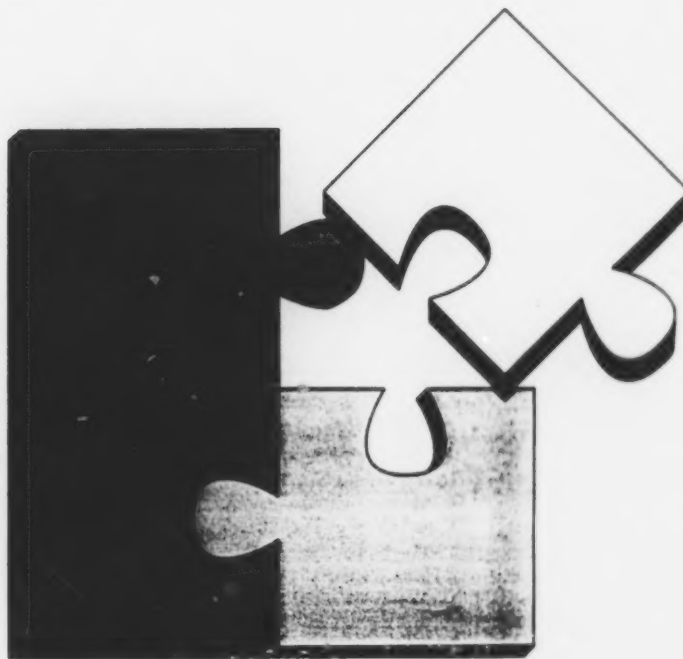
## Appendix 4

### *Evaluation Report Training Sessions*

# **Developing Culturally Competent Programs for Children with Special Needs**

Part 2

September 2, 1993

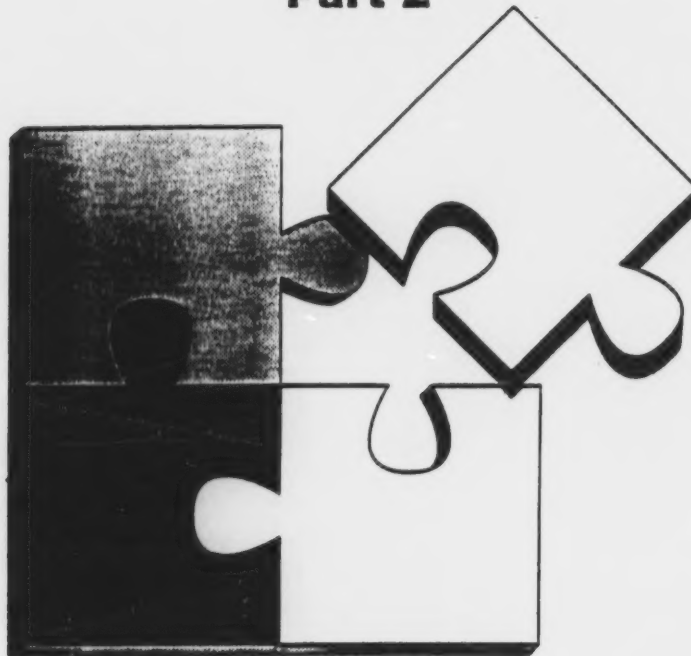


New York State Department of Health  
Bureau of Child and Adolescent Health

**Evaluation Report  
Training Sessions**

**Developing Culturally Competent  
Programs for Children with  
Special Needs**

**Part 2**



New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208, Corning Tower Building  
Empire State Plaza  
Albany, N.Y. 12237  
September 2, 1993

Report Prepared by:

Mary Huber, Project Director  
Partners in Health: Self-Help/Mutual  
Support for Culturally Diverse  
Children with Special Health Care  
Needs and Their Families.

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Disabilities and Their Families

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## INTRODUCTION

This report documents the planning and delivery of a second training series the New York State Department of Health, Bureau of Child and Adolescent Health, undertook in the fall of 1992 to increase the cultural competence of its Children with Special Health Care Needs services system. Topics in this report include: training, techniques, evaluation, and progress in cultural competence from programs that participated in the previous session.

The sessions were conducted as part of the work plan for the Federal Maternal and Child Health Bureau (MCHB) SPRANS grant, **Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families (PIH)**. Entitled **Developing Culturally Competent Programs for Children with Special Health Needs**, the programs were conducted in three sites across the state. Participants (n=116) included the following:

- 1) Staff of the 12 case management programs operated by the Physically Handicapped Children's Program (PHCP), the state's Title V Children with Special Health Care Needs Program. The purpose of case management is to assist families to coordinate a wide range of services and programs families may find useful in caring for their children with special health needs.
- 2) Staff from the three self-help clearinghouses that comprise the Partners in Health demonstration sites. Self-help clearinghouses link families to informal supports, other families who are also caring for children with special health needs.
- 3) PHCP staff from counties that do not have case management programs.
- 4) Staff of the Early Intervention Program (EIP), and Infant-Child Health Assessment Program (IHAP), which are designed to identify, locate, screen and track infants with, or at risk for, physical or developmental disabilities.

Meetings were scheduled for three regions of the state; sites and dates were:

|                                  |                    |
|----------------------------------|--------------------|
| Ronkonkoma (Long Island)         | September 9, 1992  |
| Albany (eastern New York State)  | September 10, 1992 |
| Batavia (western New York State) | September 11, 1992 |

## NEED FOR THE TRAINING

The need for the sessions flowed from recent Title V mandates that call for maternal and child health services that are family centered, community based, culturally competent, and effectively coordinated. The definition used to guide the development of culturally competence services is taken from the monograph, *Developing Culturally Competent Programs for Families of Children with Special Health Needs* (Roberts, et al., 1990). As defined in that publication, "cultural competence refers to a program's ability to honor and respect those beliefs, interpersonal styles, attitudes and behaviors both of families who are clients and the multicultural staff who are providing services. In so doing, it incorporates these values at the levels of policy, administration and practice (p. 4)."

In fulfillment of the Title V mandate, in 1990 New York State's PHCP developed a plan to improve services to children who are culturally diverse. It contains the following goal and objectives:

Goal: Implement 12 pilot projects in New York State that provide family centered, community based case management services that are culturally sensitive and culturally competent.

### Objectives:

1. Develop a clear policy statement of the need for culturally competent programs.
2. Disseminate policy statement to county projects.
3. Ask projects to identify culturally diverse populations within catchment areas.
4. Ask projects to identify a particular cultural group and provide special outreach services to them.
5. Build in the need for cultural diversity/sensitivity in staff job qualifications; assist counties in developing culturally competent job descriptions.
6. Train current staff in cultural sensitivity.
7. Assist in recruiting culturally diverse staff.



In addition to fulfilling some of the above objectives, the sessions were also designed to fulfill the training needs outlined in PIH.

### THE CHALLENGE OF PROVIDING TRAINING IN CULTURAL COMPETENCY

This was the third training session on cultural competency sponsored by the Bureau of Child and Adolescent Health for service providers who work with families who have children with special health care needs. The first session was held in June of 1991 and focused on outreach strategies to culturally diverse families, particularly as it related to engaging them in self-help/mutual support networks. Only the three self-help clearinghouses and four case management projects involved in **Partners in Health** participated. While this session was a helpful starting point, it was necessary to provide training on cultural competency for all case management sites and to broaden the focus to include case management services.

A second series of one-day workshops was conducted in three regions of the state in September of 1991. Participation was broadened to include staff of all 12 case management programs operated by PHCP as well as staff from the three PIH self-help clearinghouses. As a concluding activity, the case management projects developed a brief work plan that included cultural competency in the areas of policy, outreach, training, or service delivery. These work plans became a part of the programs' contractual agreement with DOH for the following year.

The third series of trainings was designed to capitalize on progress made by the case management projects by providing an opportunity for them to share their experiences with projects that were just beginning, but the goals remained essentially the same as for the second series: 1) to create a general awareness of cultural competency; and 2) to translate that awareness into program practice.

### SPEAKERS

In order to provide continuity, Richard Roberts, Ph.D., who was one of the co-trainers in the fall of 1991, returned as a trainer. Roberts is co-director of the Early Intervention Research Institute of

Utah State University where he directs the research and evaluation components of the Developmental Center for Handicapped Persons. He is the former chairperson of the MCHB Work Group on Cultural Competency. Among other experiences, his knowledge of cultural competency is grounded in his activities developing early intervention programs among native Hawaiians and among American Indians in the western United States.

Joining Dr. Roberts as a lead trainer was Gloria Jimpson, R.N., M.S., of the New York State Department of Health. Ms. Jimpson has designed and presented training in multicultural issues at a local college. She also has extensive experience working with culturally diverse populations in the public school system and community organizations. She is a member of the speaker's bureau for the Regional Association for Minorities in the Professions, which seeks to bring culturally diverse people into the health field.

At each site, a group of local culturally diverse parents who have children with special health needs served as consultants.

### PARTICIPANTS

The PIH grant was designed to provide training on cultural competency for the four case management projects and three self-help clearinghouses that constitute the demonstration sites for PIH. However, PIH funds provided a base that could be used to extend the audience. The Early Intervention Program supplemented PIH funds and made expansion to a larger audience possible.

#### Number of Attendees:

|                            |                               |          |
|----------------------------|-------------------------------|----------|
| PHCP Case Management Staff | Self-Help Clearinghouse Staff |          |
| 36                         | 6                             |          |
| Other PHCP Staff           | IHAP Staff                    | EI Staff |
| 15                         | 24                            | 31       |
| DOH Staff                  |                               |          |
| 7                          |                               |          |

Total Participants = 116

### Ethnicity of Attendees

As part of the evaluation, participants were invited to indicate their ethnocultural background. Of those who responded (73 of 89 participants, 89%), the following identification was given:

65 White      6 Black      1 Native American  
1 Black Hispanic

### BEHAVIORAL OBJECTIVES OF TRAINING

Similar to the training presented in the fall of 1991, content for this training derived from two publications, *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (Cross, et al., 1989), and *Developing Culturally Competent Programs for Families of Children with Special Health Needs* (Roberts, et al., 1990).

Discussions among PHCP administrative staff, the project director, and the trainers resulted in establishing the following behavioral objectives and key content areas.

Participants will be able to:

1. Define a culturally competent system of care.
2. Describe the continuum of cultural competence from cultural destructiveness to cultural competence.
3. Describe the relationship between cultural competence and family centered, community based, coordinated care.
4. Provide at least one example of culturally competent care in each of the areas of policy, training and practice.
5. Describe the difference between models of intervention that use cultural stereotyping and ones that are truly culturally competent.

6. Relate the principles of culturally competent practice to one area of their own professional practice with a plan for intervention.

#### COUNTY PROGRESS AND NEEDS ASSESSMENT

To assist in planning, Dr. Roberts prepared a brief questionnaire that was sent to the case management program coordinators in each of the counties that had participated in the previous training. (See copy in the appendix.) Its purpose was two-fold: 1) to ascertain progress on the cultural competence continuum among projects that had attended the previous year's training; and 2) to determine topics that should be addressed in the sessions.

A sampling of responses illustrates progress had been made within one year.

- ☐ Suffolk County linked with a Hispanic agency to increase referrals.
- ☐ Orleans County networked with the Rural New York Farmworkers' Organization for assistance in working with a Hispanic migrant family.
- ☐ New York City advertised on a Haitian radio station, and distributed its program brochure translated into Haitian and Spanish. Staff made personal visits to a Haitian community center, the Minority Aids Conference, the Immigrants Rights Project and also targeted for outreach hospitals that had a high concentration of immigrant clients, such as Dominicans at Columbus Presbyterian Hospital and Lincoln Hospital, Haitians at Kings County Hospital and Hispanics and Chinese at Governor Hospital. The program also worked with the Asian Pacific Islanders against Aids, the American Indian Community Center, and Centro Medicino Clinic in the Bronx.
- ☐ A case manager in New York City prepared a resource guide of services available to undocumented residents and trained other DOH staff in the scope of the services and methods for accessing them.
- ☐ Niagara County completed the steps it had outlined to reach culturally diverse families including meeting with area clergy to describe program, visiting WIC sites and the Tuscarora Reservation on at least a quarterly basis, and distributing flyers in the offices of the county's department of social services. Staff is increasing its



knowledge of Native American culture by attending courses at a local community college that are presented by Native Americans. It also hired a care coordinator from a diverse culture.

□ Albany County worked with the Partners in Health self-help clearinghouse to sponsor a self-help day and fair at a community center located in Albany's black neighborhood. It developed special outreach to Hispanic and Haitian families.

□ Rural Yates County increased its knowledge of the Mennonite community and their beliefs and worked with the midwives who deliver babies in the Mennonite community to increase their awareness of PHCP and case management. The program has developed a relationship with leaders in the Mennonite Community who serve as mediators in communication between families and the PHC Case Management Program.

□ Onondaga County hired a Spanish-speaking case manager who in addition to working with Latino families translated the release of information forms into Spanish; collected Spanish brochures from other agencies; purchased a Spanish/English medical dictionary to use in translating medical information for families; translated the Individualized Family Service Plans (IFSPs) into Spanish; accompanies Spanish-speaking families to appointments and arranges for other translators to accompany clients to medical appointments when she was not available. The clerical staff learned some basic Spanish phrases so they could take phone messages and consequently developed increased sensitivity to the difficulties experienced by families who must communicate with the health department in a secondary language.

□ Tompkins County began using a family diagram to assist in understanding family structure and resources.

### TRAINING NEEDS

The needs listed by the respondents were often outside the scope of the sessions. Several requested information on specific cultures. New York City requested training on immigrants' rights and the legal status of undocumented residents who have a child with special needs. Methods for responding to these needs will be considered in the future.

## APPROACH

The presenters used a variety of methods to present the material: lecture, discussion between the presenters and between the presenters and the participants, small group work, and input from the parent consultants. As a culminating activity, participants began or expanded the process of developing culturally competent programs for their local sites in one area -- policy, training, assessment, or outreach.

In addition, each participant received a copy of the workbook that accompanies *Developing Culturally Competent Programs for Families of Children with Special Health Needs* for reference and continued study at local sites. The article "Cultural Dimensions of Feeding Relationships" (*Zero to Three*, June 1992), was distributed as a supplement to the discussion on culture. A bibliography on cultural competency completed the information packet.

## PARTICIPANT EVALUATIONS

The following section summarizes the evaluation forms completed by participants.

Participants rated several categories with a numerical score that ranged from one (poor) to four (excellent). They are reported here on an individual and aggregate site basis.

| Ronkonkoma                | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 2.84              | 1 - 4        |
| 2. Method of Presentation | 3.17              | 2 - 4        |
| 3. Handouts               | 3.05              | 2 - 4        |
| 4. Overall Evaluation     | 2.88              | 2 - 4        |
| Albany                    | <u>Mean Score</u> | <u>Range</u> |
| 1. Program Content        | 2.26              | 2 - 4        |
| 2. Method of Presentation | 2.75              | 2 - 4        |
| 3. Handouts               | 2.81              | 2 - 4        |
| 4. Overall Evaluation     | 2.98              | 2 - 4        |



| Batavia                   | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 3.07              | 2 - 4        |
| 2. Method of Presentation | 3.22              | 2 - 4        |
| 3. Handouts               | 3.05              | 2 - 4        |
| 4. Overall Evaluation     | 3.12              | 2 - 4        |

| Average of Three Sites    | <u>Mean Score</u> |
|---------------------------|-------------------|
| 1. Program Content        | 2.72              |
| 2. Method of Presentation | 3.05              |
| 3. Handouts               | 2.97              |
| 4. Overall Evaluation     | 2.99              |

The conference planners recognized that they were taking a risk in presenting a program that repeated information from a previous session to some of the same participants. To determine whether previous participation affected scores, an analysis was also completed that shows the difference between the those who attended the fall 1991 sessions and those who did not. The following tables indicates that the repetition did not make a significant difference in the response.

Scores from those who attended previous session:

|                           | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 2.9               | 2 - 4        |
| 2. Method of Presentation | 3.37              | 2 - 4        |
| 3. Handouts               | 3.10              | 2 - 4        |
| 4. Overall Evaluation     | 2.92              | 2 - 4        |

Scores from those who did not attend previous session:

|                           | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 3.02              | 1 - 4        |
| 2. Method of Presentation | 2.85              | 2 - 4        |
| 3. Handouts               | 2.83              | 2 - 4        |
| 4. Overall Evaluation     | 3.14              | 1 - 4        |

In addition to rating the conference with a numerical score, participants also responded to a series of open-ended questions. Responses are summarized below.

### **Best thing about the session:**

Many participants (n=30) cited being able to talk with colleagues from other counties about their specific programs and services as the best thing about the session. Sharing of ideas was built into many aspects of the program, including having representatives of PHCP case management programs describe progress on their cultural competency work plan from the previous year, discussing topics such as outreach to culturally diverse families in small groups, beginning the program with an ice breaker (see appendix), and providing sufficient time at lunch for people to visit.

Participants also mentioned raising consciousness about cultural competence; an exercise that analyzed the distribution of power participants' agencies share among three entities: the agency itself, families, and the community; the input from parents; the practicality and adaptability of material presented; and practical approaches to reachout.

### **Ways session could have been improved:**

Approximately half the respondents did not supply information on this topic. As with the previous session, the most common response (n=8) is that there should be more specificity on particular cultural groups, how they respond to children with special needs, and how service providers should respond to them. Four respondents, all from the first training site, thought the content was too basic. Said one, "Public health nurses are culturally competent. You are speaking to the converted." Based on this comment and discussion during the first session, the trainers did revamp their approach for the next two sites by eliminating some of the early exercises and using that time for skill development. This was accomplished using the outline provided in *The Workbook for Developing Culturally Competent Programs for Families of children with Special Needs* (Roberts, et al. 1990). Other comments were single responses which will be reviewed when future training is presented.

### **Did you learn of methods for developing culturally competent programs that are needed or missing in your program?**

Sixty-two respondents replied yes, 16 replied no (8 of them were from the Long Island site), and 10 respondents gave no reply.

Many respondents cited examples of these methods, which cover a broad range of items, and, in fact, do reflect that the goals and objectives of the session were achieved for many. Items cited are:

- Develop outreach goals to Hispanic community; send letter and brochures to groups, services in this area. Try to develop list of Spanish-speaking individuals to use as interpreters;
- Recognize cultural pockets in our county we had not approached;
- Print things in different languages;
- Revise agency policy to address issue;
- Approach members of culturally diverse families to be on advisory boards;
- Solicit volunteer interpreters;
- Step outside my own belief system on how things are done and into how families feel things should be done; and
- There is a black community between Ontario and Seneca counties that both tend to forget. We'll focus on that community.

Based on this session, are there applications of culturally competent practice that you intend to use in your professional practice?

59 yes      6 no      25 no answer

In response to this question, respondents listed many of the items cited in the previous response. Practices include:

- More outreach to Hispanic community;
- Being less apt to judge, assume;
- Becoming known to human service agencies that serve culturally diverse people;
- Planning to address each parent as competent and able to change;
- Instead of talking "at" people, I will take a look at what their goals are first; and
- Keeping in mind that families are competent caregivers.

## Obstacles to implementing:

Only three participants responded to this question. One cited a lack of interest on the part of the administration and supervisor. Two noted a lack of resources -- funding and staff to expand into new areas.

## General comments:

Many participants took the opportunity to respond to an open-ended question that invited comments on the session. Typical of the responses are the following:

- "Need much more training" (Long Island);  
"Well prepared and presented, interesting and informative."  
(Long Island);
- "I was excited by the presentation but at the same time  
dismayed at some of the rigidity and disrespect of my  
colleagues." (Long Island);
- "Please do another one next year " (Albany);
- "You need to define what you mean by "culture. Sometimes  
Richard uses it when he refers to personality differences which  
is quite different." (Albany)
- "Mr. Roberts apologizes too much for being a white American.  
He should be proud of his culture instead of calling himself a  
Racist. I think of a Racist as someone who thinks his race is  
superior to all other races." (Albany)
- "I think it may be helpful to talk more about what the different  
cultures actually are like. . ." (Albany)
- "Methods of presentation were excellent." (Batavia)
- "A great beginning--we need to keep working on this."  
(Batavia)

## COUNTY WORK PLANS

As a culminating activity, each county staff developed a plan to enhance their program's cultural competency. In most counties, all personnel from the same county developed the plan. In a few instances, staff from several counties worked together. The information in italics indicates the programs represented by each county.

## **Albany County**

### *PHCP Case Management and IHAP*

1. To promote more family involvement, we will make sure that parents are invited to case conferences and have a real say in the decisions made about their child.
2. Promote parent involvement in the review of program guidelines for case management.
3. Promote more parental involvement with the actual care plan that nurses develop.
4. Obtain copy of the Community Health Assessment and read it.

## **Broome County**

### *(Early Intervention)*

1. Target outreach to low income, inner city
2. To learn about culturally diverse populations, study data from breast cancer program, which has good demographics.
3. Analyze radio stations to find those that appeal to culturally diverse populations.
4. Utilize existing health department programs such as hospitals.

## **Cattaraugus, Orleans, and Yates Counties**

### *(PHCP and Early Intervention in all counties)*

#### Action Steps:

1. Visit the local physicians.
2. Write letter to the clergy and ask them to distribute pamphlets and place information in bulletins.
3. Provide in-service for Head Start home visitors.
4. Talk with day care or nursery school staff.
5. Meet with Preschool Special Education Committee in communities and CSE.
6. Make contact with OB personnel at hospitals.

7. Contact formal and informal community leaders.
8. Attend community meetings for human services groups.
9. Advertise in libraries, laundromats, newspapers.
10. Contact service clubs who are often aware of target population through their activities.
11. Place information in school newsletters.
12. Contact Cooperative Extension and WIC
13. Incorporate into higher education curriculum by visiting local colleges.

**Delaware County**  
*(Early Intervention and IHAP)*

1. Target rural poor.
2. Work with Kiwanis toy lending program to help identify families.
3. Work with cooperative extension nutrition program to extend involvement in parent education.
4. Build up among children knowledge of heritage as vehicle for positive child development

**Dutchess County**  
*(IHAP and EI nurse)*

1. Carry Spanish editions of WIC pamphlet in car for easy distribution.
2. Bring to health guidance team meetings list of "inclusion of parents" ideas from this workshop.
3. Continue to think of myself as a 'recovering racist' as a clear reminder of my path.



## **Erie County**

*(Early Intervention Service Coordination Program)*

**Audience:** Hispanic Community

1. Currently trying to hire Hispanic staff.
2. Initiate cooperation with community agency.
3. Utilize Hispanic media.
4. Translate brochures.
5. Provide outreach through attendance at cultural events and working with leaders in the Hispanic community
6. Distribute information through churches, civic clubs, Head Start, day care, Columbia Hospital's Well Baby Clinic; school districts, WIC, and grocery stores.
7. Identify a Hispanic parent to serve on local early intervention coordinating council.
8. Provide in-service training to staff on cultural competency.

## **Erie, Chautauqua, and Cayuga Counties**

*(Participants in this group were a public health nurse from Cayuga County, EI and PHCP staff in Chautauqua County, and staff from the Erie County PHC Case Management Program.)*

**Audience:** Hispanic Community

1. Translate materials into Spanish.
2. Hire Spanish-speaking staff.
3. Provide attitude awareness exercises at staff inservices.
4. Assess resource, i.e., staff, administrative priorities, political realities and decide when time is right to implement change or influence administration.

5. Discuss possibilities with culturally diverse parents. Discuss possibilities for self-advocacy.

#### **Essex**

*(PHCP and Early Intervention)*

1. Create general public awareness among poor.
2. Put brochures everywhere.
3. Try to make more frequent contact with families.
4. Review municipal health services plan to assess county demographics.

#### **Montgomery County**

*(IHAP and PHCP)*

1. Get programs off the ground.

#### **Monroe County**

*(Early Intervention)*

Audience: 0 - 2 who are falling through the cracks, particularly inner city population

#### Action Steps:

- Involve pediatricians in outreach efforts.
- Translate brochures into Spanish at a basic reading level.
- Participate in hospital grand rounds.
- Hit the streets. Possible sites include antepartal classes, emergency rooms, drug rehabilitation centers.
- Develop public awareness information through pamphlets and public service announcements.

#### Distribute information to:

- WIC sites
- Pediatricians' offices
- DSS
- Grocery stores
- Churches
- Urban League.

**Onondaga County**  
*(PHCP Case Management)*

1. Contact groups that work with Russian immigrants and Southeast Asians.
2. Get on the program to address county nurses' organization.
3. Contact Onondaga Reservation.

**Putnam County**  
*(Early Intervention)*

1. Create an Early Intervention Coordinating Council which is comprised of equal numbers of family members, agency or political representatives, and service providers.
2. Create a culturally competent brochure or brochures describing the program.
3. Provide inservice training to IHAP and EI staff on cultural competency.

**Rensselaer County**  
*(Early Intervention and IHAP)*

1. Provide outreach to Hispanic community.
2. Visit community centers and leaders.
3. Obtain Hispanic videos that would be helpful to families.
4. Place culturally diverse families on local early intervention coordinating council.
5. Study municipal health services plan to learn more about culturally diverse in the community.
6. Make copies of Spanish language resources.
7. Visit public housing.

**Saratoga County**  
*(PHCP)*

1. Introduce PHCP to a new group, i.e., junior high students.
2. Distribute PHCP information at immunization clinics.
3. Send PHCP information to county pediatricians.  
*(Early Intervention)*

1. Start the early intervention coordinating council and have four families on the council.

**Schenectady County**  
*(Early Intervention and IHAP)*

1. Learn what the International Center does - who it services, and how can it be of assistance to the Public Health Department (and other referral agencies for people of different cultures). This is because we do a lot of referring -- we let families do the calling, but many times we do the referring directly.
2. Invite guest speakers to monthly staff education meeting - gain understanding of diverse cultures - invite speakers from the referral agencies.

**Seneca, Ontario, and Schuyler Counties**  
*(PHCP and IHAP in Seneca County; IHAP and Early Intervention in Ontario County; generic services in Schuyler County)*

1. Identify cultural groups that will be served by examining the municipal health services plan and census tract data from the Bureau of Information Services. Analyze this information by disease, by zip code, and by demographics.
2. Create awareness of the program by reaching out to the Board of Health, community groups, professional groups, and parents who are adopting culturally diverse children.
3. Set up a parent advocacy group.

### **Suffolk County**

*(Early Intervention and IHAP)*

1. Take classes in Spanish (IHAP).
2. Meet with Spanish program several times.
3. Search for Spanish-speaking staff.
4. Integrate all programs.
5. Attempt to hire culturally diverse nurses (Early Intervention)

### **Tompkins County**

*(PHCP Case Managers and Early Intervention)*

Develop outreach materials directed to Hispanic population:

- letter with program brochures targeted to specific agencies in this community, including:
  - GIAC (Greater Ithaca Activities Center)
  - English as a Second Language Class
  - Refugee Assistance Program
  - WIC
  - WCC
  - Headstart
- Request list of interpreters including students at Cornell, Ithaca College, Tompkins County Community College at Cornell, Ithaca College, TC3 and families within the community.
- Request to present to these groups info related to both programs.
- Adopt materials directed by Hispanic Community.

For additional information, contact:

Mary Huber  
Bureau of Child and Adolescent Health  
NYS Department of Health  
Corning Tower, Room 208  
Empire State Plaza  
Albany, NY 12237  
(518) 474-6781



## Session Evaluation

Developing Culturally Competent Programs for Children with Special  
Health Needs September 1992

Please rate each of the following:

|                                  | Excellent | Good | Fair | Poor |
|----------------------------------|-----------|------|------|------|
| 1. Program Content               | 1         | 2    | 3    | 4    |
| 2. Method of Presentation        | 1         | 2    | 3    | 4    |
| 3. Handouts                      | 1         | 2    | 3    | 4    |
| 4. Overall evaluation of session | 1         | 2    | 3    | 4    |

5. The best thing about this session was:

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6. This session could have been improved by:

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7. Did you learn of methods of developing culturally competent  
programs that are needed or missing in your program?

\_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, list specific examples:

---

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8. Based on this session, are there applications of culturally competent practice that you intend to use in your professional practice? \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, please list specific practices?

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If no, list specific obstacles to implementation:

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9. Please use this space for other comments you would like to make about this training session in cultural competency.

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**Survey of Session Participants' Ethnocultural Background**  
The Maternal and Child Health Bureau, USDHHS, has requested that we collect the following data. This information is for statistical purposes only and is purely voluntary. Check as appropriate.

|                      |             |                       |
|----------------------|-------------|-----------------------|
| _____ White          | _____ Black | _____ Black Hispanic  |
| _____ White Hispanic | _____ Asian | _____ Native American |
| _____ Other          |             |                       |

**Thank you for taking the time to evaluate this session.**

## BIBLIOGRAPHY

### DEVELOPING CULTURALLY COMPETENT PROGRAMS

Cross, T., Bazron, B., Dennis, K., and Isaacs, M., *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, CAASP Technical Assistance Center, Georgetown University Child Development Center, Washington, DC, 1989. Although this monograph focuses on the issue of emotional disturbance, it provides a philosophical framework and practical ideas for improving service delivery to children of color for all issues.

Available from: CAASP Technical Assistance Center  
Georgetown University Child Development Center  
3800 Reservoir Road, NW  
Washington, DC 20007  
(202) 687-8635

Price: \$ 8.00 plus shipping and handling

Malach, R., Segel, N., and Thomas, T., *Overcoming Obstacles and Improving Outcomes: Early Intervention Services for Indian Children with Special Needs*, Southwest Communication Resources, Bernalillo, New Mexico, 1989. This publication identifies and discusses some important issues that must be considered when providing early intervention services to American Indian infants and their families. The focus is on issues related to the cultural differences between Indians and non-Indians and how this affects the provision of early intervention services.

Available from: Southwest Communication Resources  
PO Box 788  
Bernalillo, NM 37004  
(505) 867-3396

Price: \$10.00 plus 10% postage/handling

National Center for Youth and Disabilities, *Race and Ethnicity: Issues for Adolescents with Chronic Illnesses and Disabilities*, National Center for Youth and Disabilities, 1991. Examines health, education, and vocational issues as well as general psychosocial issues for adolescents and parents from various ethnic and racial groups.

Available from: National Center for Youth with Disabilities  
Box 7212 UMHC  
Harvard Street at East River Road  
Minneapolis, MN 55455  
(800) 333-6293

Price: \$3.50

Roberts, et al., *Developing Culturally Competent Programs for Children with Special Needs*, Georgetown University Child Development Center, Washington, DC, 1990. (Monograph) Discusses general issues in developing culturally competent services in relationship to community-based family-centered care and specific issues of policy and practice related to culturally competent services. Presents models of existing programs that are culturally competent.

Available from: CAASP  
(see above)

Price: \$4.00

Roberts, et al., *Workbook for Developing Culturally Competent Programs for Children with Special Needs*, Georgetown University Child Development Center, Washington, DC, 1990. (Workbook) Designed to accompany the above monograph, the workbook provides a means for programs to examine their policies and practices and to target areas where cultural competence can be improved.

Available from: CAASP  
(see above)

Price: \$4.00

## BIBLIOGRAPHY

### DEVELOPING CULTURALLY COMPETENT PROGRAMS

Cross, T., Bazron, B., Dennis, K., and Isaacs, M., Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who are Severely Emotionally Disturbed, CAASP Technical Assistance Center, Georgetown University Child Development Center, Washington, DC, 1989. Although this monograph focuses on the issue of emotional disturbance, it provides a philosophical framework and practical ideas for improving service delivery to children of color for all issues.

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Available from: CAASP  
(see above)

Price: \$4.00

Roberts, et al., Developing Culturally Competent Programs for Children with Special Needs, Georgetown University Child Development Center, Washington, DC, 1990. (Workbook)

Available from: CAASP  
(see above)

Price: \$4.00

For additional information, contact:

Mary Huber  
Bureau of Child and Adolescent Health  
NYS Department of Health  
Corning Tower, Room 208  
Empire State Plaza  
Albany, NY 12237  
(518) 474-6781





# STATE OF NEW YORK DEPARTMENT OF HEALTH

Coming Tower The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Lloyd F. Novick, M.D., M.P.H.  
Director  
Diana Jones Ritter  
Executive Deputy Director

August 11, 1992

Dear PHCP Case Management Coordinators:

Last fall you participated in a one-day workshop sponsored by the New York State Department of Health entitled, "Developing Culturally Competent Systems of Care for Families of Children with Special Health Needs." The conference leaders were Richard Roberts and Gina Barclay McLaughlin. As you know, there will be a follow-up meeting this September to continue our efforts to develop programs within communities that provide services to families in ways that respect their cultural diversity. This year's workshops will be led by Richard Roberts and Gloria Jimpson.

In preparation for this second workshop, it would be helpful for the facilitators to have some sense from PHCP Coordinators as to how they have been able to use the material presented last year in their programs. This may range from "not at all" to "we have completely revised our policies, family involvement, outreach practice and training." We suspect that for most programs it is somewhere on a continuum in between these two.

It would be most helpful if you could spend a couple of minutes providing the information requested below. In some cases, it would be helpful if you discussed the question with your staff (e.g., II F) so that we can get a good representation of ideas. Our responses will help us to better suit your needs in this year's activities. Thanks for your time.

Sincerely,

Mary Huber  
Director  
Partners in Health

mh060

Part I Test Your Memory:

How would you define cultural competence now?

What do you see as the relationship between cultural competency and the mandate for family centered, community based, coordinated care for children with special health needs?

## Part II Putting Great Ideas Into Action

At the close of last year's meeting, you were asked to identify a plan for incorporating the ideas of cultural competency into your program. Staff of each program had one or two things they were going to try.

A. Have you had a chance to try any of the ideas in your program? If so, which ones?

B. How have these ideas been received by your staff?

C. For those ideas you tried, what has been the result?

D. What challenges have you faced in trying to change parts of your program to incorporate your plan into ongoing operations?

E. Were you able to effect change within your organization or your own case load that led to a more culturally competent delivery of services - changes you might not have implemented without the training?

F. What additional topics would you like to see covered in this year's efforts that would make it easier for you to move your program along the cultural competence continuum?

Which session will you be attending? (Check one)  
\_\_\_\_\_ Long Island      \_\_\_\_\_ Albany      \_\_\_\_\_ Batavia

Thank you for completing this form. Please return it by  
Wednesday, August 26th, to:

Mary Huber, Director  
Partners in Health  
New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208 Corning Tower Building  
Albany, NY 12237-0618

## Agenda

|       |                                   |
|-------|-----------------------------------|
| 10:00 | Ice Breaker                       |
| 10:20 | Introduction of Facilitators      |
| 10:30 | Group Activity                    |
| 11:00 | Break                             |
| 11:10 | Continuation of Group Activity    |
| 11:30 | Discussion of Cultural Competency |
| 12:30 | Lunch                             |
| 1:30  | Presentation by Counties          |
| 2:00  | Work Groups                       |
| 3:30  | Evaluation and Summary            |

The conference is jointly sponsored by:  
**Federal Part H (PL 102-119) Program for Infants and  
Toddlers with disabilities and Their Families;  
Children with Special Health Care Needs System  
Development and Expansion in New York State, Project  
PHS-3038; and by  
Partners in Health: Self-Help/Mutual Support for Culturally  
Diverse Children with Special Health Needs and  
Their Families, Project #MCJ367034919 from the  
Maternal and Child Health Program  
(Title V, Social Security Act)  
Health Resources and Services Administration,  
Department of Health and Human Services**



## ICEBREAKER

### Find Someone who . . .

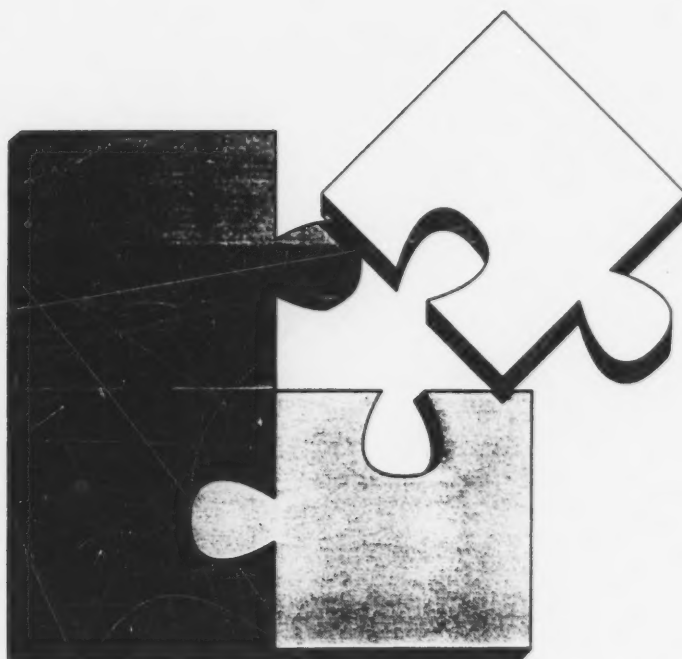
|                                                                                                              |                                                                                                            |                                                                                                                         |                                                                                                                     |
|--------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|
| <b>Has relatives that live in a country outside the U.S.</b><br><br>Name: _____                              | <b>Can name three groups who are involved in the war in Bosnia.</b><br><br>Name: _____                     | <b>Likes to eat food from the country of India.</b><br><br>Name: _____                                                  | <b>Has, and listens to, music from another culture.</b><br><br>Name: _____                                          |
| <b>Has provided professional services to someone from a culture other than one's own.</b><br><br>Name: _____ | <b>Wears clothing worn traditionally by people from a culture other than one's own.</b><br><br>Name: _____ | <b>Has been to a workshop focusing on cross cultural communication or race relations.</b><br><br>Name: _____            | <b>Has learned a dance from a culture other than one's own.</b><br><br>Name: _____                                  |
| <b>Has visited a Native American reservation.</b><br><br>Name: _____                                         | <b>Has been to a black gospel choir concert.</b><br><br>Name: _____                                        | <b>Has lived in a country outside the U.S. for one or more years.</b><br><br>Name: _____                                | <b>Eats Mexican food at least once per month.</b><br><br>Name: _____                                                |
| <b>Has had a conversation with a teenager from another culture.</b><br><br>Name: _____                       | <b>Speaks three or more languages.</b><br><br>Name: _____                                                  | <b>Has read three or more books in the last year that take place in or describe another culture.</b><br><br>Name: _____ | <b>Works in a setting where over 50% of the clients are from a culture other than one's own.</b><br><br>Name: _____ |
| <b>Has been to a movie that takes place in another culture.</b><br><br>Name: _____                           | <b>Lives in a neighborhood that has two or more cultural groups represented.</b><br><br>Name: _____        | <b>Owens a dictionary in a language other than English.</b><br><br>Name: _____                                          | <b>Traveled the farthest to get to this workshop.</b><br><br>Name: _____                                            |

---

## **Appendix 5**

### ***Evaluation Report Training Sessions***

# **Empowering Families Through Self-Help/Mutual Support**



New York State Department of Health  
Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

March 1, 1993

Dear Participants of "Empowering Families through Self-Help/Mutual Support":

Enclosed is a report of the conference you attended in June of 1992 on how to enhance parent-to-parent support.

In particular, please note the county work plans which begin on page 12. Please review the plan developed for your county as a means of assessing what your program has done to make it possible for parents to connect to each other, an important component of family centered care.

If you would like technical assistance in implementing any parent support activities you may contact Mary Huber at (518) 474-6781.

Sincerely,

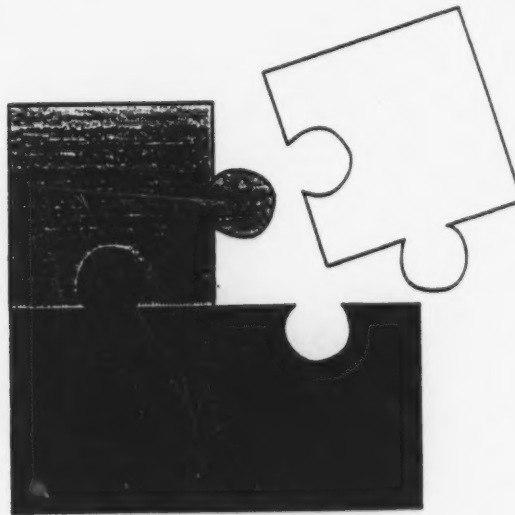
Frank Zollo  
Director, Early Intervention Program  
Bureau of Child and Adolescent Health

Nancy Kehoe  
Director, Physically Handicapped  
Children's Program  
Bureau of Child and Adolescent Health

Enclosure  
MH114

*Evaluation Report  
Training Sessions*

*Empowering Families Through  
Self-Help/Mutual Support*



December 15, 1992

New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208 Corning Tower Building  
Empire State Plaza  
Albany, NY 12237

This program was supported in part by Project #MCJ367034010  
from  
the Maternal and Child Health Bureau  
(Title V, Social Security Act),  
Health Resources and Services Administration,  
Department of Health and Human Services

and

Federal Part H (PL 102-119) Program for  
Infants and Toddlers with  
Disabilities and their Families

Prepared by:

Mary Huber, M.A., Project Director

Special thanks to the parents who told their stories and helped us see so much.

Lorraine Blum  
Pamela Cardinal  
Linda Carrol  
Maryann Cucciaio  
Monica Harrison  
Barbara Hoffman  
Jennifer Huff  
Susan Mahserjian- Smith  
Marie O'Malley  
Dee Thorburn  
Lynn Turner  
Pat Vanasco



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## INTRODUCTION

This report, *Empowering Parents* describes a training program that the New York State Department of Health, Bureau of Child and Adolescent Health, undertook to increase the knowledge and skills of service providers related to the facilitation of parent-to-parent networks for children with special health care needs in the health and human services system. Topics in this report include: training objectives, techniques, evaluation, follow-up activities, and a bibliography.

The sessions were conducted as part of the work plan for the Federal Maternal and Child Health Bureau (MCHB) SPRANS grant, **Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families (PIH)**. Entitled **Empowering Families through Self-Help/Mutual Support**, the programs were conducted in three sites across New York State. Participants were staff from the three self-help clearinghouses that comprise the Partners in Health demonstration sites and staff from local county health units who work in a variety of programs for children with special needs. This included staff of the 12 case management programs operated by the Physically Handicapped Children's Program (PHCP), the state's Title V Children with Special Health Care Needs program; PHCP staff from counties that do not have case management programs; staff of the Early Intervention Program (EIP); and staff from the Infant Health Assessment Program (IHAP).

Self-help clearinghouses link families to informal supports and other families who are caring for children with special health needs. The purpose of PHCP case management is to assist families to coordinate a wide range of services and programs families may find useful in caring for their children with special health needs. EIP is a program of early intervention services for infants and toddlers under the age of three with developmental delays, as well as related services for their families. IHAP is a program designed to identify, locate, screen and track infants with, or at risk for, physical or developmental disabilities.

Meeting sites and dates were:

|            |               |                    |
|------------|---------------|--------------------|
| Albany     | June 5, 1992  | (Eastern New York) |
| Batavia    | June 9, 1992  | (Western New York) |
| Ronkonkoma | June 12, 1992 | (Long Island)      |

This was the second training on self-help/mutual support sponsored by Partners in Health. The first was conducted in June of 1991 as part of the introductory training session for the grant's staff who would be working at the local level in four counties--Nassau, Suffolk, Albany and Niagara. Present at the first session were all self-help clearinghouse staff from those counties; PHC Case Management Program supervisory staff from Nassau and Suffolk counties; PHC Case Management Program supervisory staff and one of eight case managers from Niagara County; and the PHC Case Management Program staff in Albany County. Although these counties have been working to develop parent-to-parent supports and made some significant gains, it was important to provide additional information and to provide it for all staff, not solely supervisory staff. The second session provided an opportunity for staff from other programs for which parent-to-parent support is a vital issue to increase their understanding of the topic.

#### GENERAL NEED FOR THE TRAINING

The need for the sessions flowed from the recent Title V mandates that call for maternal and child health services that are family centered, community based, culturally competent, and effectively coordinated. The components of family centered care were summarized by the Association for the Care of Children's Health in its 1987 publication, *Family-Centered Care for Children with Special Health Care Needs*. As a guide for program development, it lists eight components of family centered care. One of them is that professionals encourage and facilitate parent-to-parent support, also known as self-help/mutual support. Such a task is not easily accomplished.

National studies show that despite the proven success of the self-help approach in improving health status, barriers to cooperation between self-help/mutual support and public health systems still exist. In preparation for the Surgeon General's Workshop on Self-Help and Public Health conducted in 1987, the research group InterStudy (1987) conducted a survey of current attitudes and beliefs on self-help and public health. While some self-help group members reported that they had supportive relationships with the public health system, many of those questioned described the relationship as "very hostile", "lots of mutual distrust", "more indifferent than hostile", and "extremely slight and inadequate."

In addition, the formal health system displays some resistance to the use of self-help/mutual support as a means to prevent health problems and improve health status. The same InterStudy report found that the health community had concerns about the medical and legal ramifications of referring clients to self-help groups and often questioned the accountability of groups. Professionals who rely on quantitative data to guide their practice often doubt the validity of the experiential knowledge that is the hallmark of self-help. As a result, health-related groups must often operate outside the professional health system, a situation that is far from ideal and deprives both service providers and parents the opportunity for productive, collaborative relationships. These general considerations determined the training content of the curriculum.

### TRAINING NEEDS OF PARTICIPANTS

In order to assess the training needs of participants and their current use of self-help/mutual support, staff designed and distributed a survey that each program (not individuals) returned with their registration. (See Appendix for a copy.) It covered two broad areas of inquiry: 1) If they connected families to self-help/mutual support and if not, why not; and 2) If they used as a referral source the *New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families*.

Of the 18 surveys that were returned, 13 programs indicated that they have connected families to self-help/mutual support. Of those that did not do so, many from rural counties indicated that the closest network was too far for families to travel. The three things programs wanted discussed at the meeting were: 1) how to cope with travel distances; 2) how to maintain group interest after initial enthusiasm has waned; and 3) the type of commonality that is best within a group, for example, in groups for children is it better to organize around similarity of disability or similarity of age. While the survey indicated that many programs make referrals, it also showed that staff did not know of the wide variety of means for encouraging parent-to-parent support and the creative ways it can develop.

The needs assessment also sought to find out if programs were using the statewide directory of self-help/mutual support that Partners in Health developed to assist in the referral process. Five programs indicated they did use it. Five referred a parent to one of

the networks; four contacted some of the resources listed in the back of the directory; two called a network contact person for information; and two programs that facilitate networks called another network to exchange information.

Twelve programs did not use the directory. Most of these programs were part of the Early Intervention Program, and indicated they did not know of its existence. This was valuable information for Partners in Health. Although the directories had been sent out six months prior to the training, somehow they had not reached the programs, perhaps because staff was just being hired at that time. Several programs in upstate rural counties indicated there were no listings of networks in their area, so the information was of no use. Another program indicated it referred all its questions to the local self-help clearinghouse, where information is more up-to-date. Again, the responses showed that users did not know of the different ways the directory could be used to connect parents to each other. As a result of these findings, copies were distributed to all participants, and a portion of the day devoted to discussing its uses.

Another type of needs assessment was conducted on the day of the training in order to make sure information was relevant. As one of the first activities, the facilitator asked participants to list the things they wanted addressed at the meeting. This list was then reviewed at the end of the meeting to make sure all topics had been covered. Topics of interest were:

- ☐ How to make referrals without breaking confidentiality;
- ☐ How to make support groups parent driven;
- ☐ How to encourage involvement in support networks when parents' time is so limited;
- ☐ How to involve dads in support networks;
- ☐ How to locate existing groups;
- ☐ How to provide economic support so that parents can attend meetings;
- ☐ How to devote resources to parent-to-parent support when resources are already limited and programs threatened with budget cutbacks; and
- ☐ How to involve culturally diverse families in self-help/mutual support when self-revelation may not be part of their culture.



All of these issues were complementary to the goals and objectives Partners in Health had established for the meeting and were addressed during the course of the session or by mailing to participants material after the meeting.

### GOALS AND OBJECTIVES

The following goals and objectives guided the meetings' discussions.

Goal: To educate staff of programs for children with special needs about the self-help/mutual support networks and their activities so that they will encourage and facilitate parent-to-parent support as one means of encouraging parent empowerment.

#### Objectives:

- ☐ To enable professionals to learn directly from parents about the importance of self-help/mutual support in caring for their children.
- ☐ To provide staff with resources that will enable them to develop self-help/mutual support groups and activities.
- ☐ To clarify the role of professionals vis-a-vis parent-to-parent support.
- ☐ To increase staff awareness of issues related to self-help/mutual support among culturally diverse families.
- ☐ To enable professionals to understand the wide variety of methods by which parent-to-parent networks can operate.
- ☐ To describe the uses of the *New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families* for linking families.

### SPEAKERS

An important premise for designing the program was that the most effective spokespersons on self-help/mutual support are



parents who are themselves members of parent-to-parent networks and can describe from their own experiential knowledge base why they are important, as well as the range of issues involved in their development and success. However, parents are often reluctant to speak in front of professionals.

A previous program sponsored by Partners in Health, entitled Partners in Policy Making, assisted staff in identifying parents who were willing to present their stories. Among other things, Partners in Policy Making is designed to give parents practice and confidence to speak before potentially intimidating audiences. At the conclusion of Partners in Policy Making, the program director asked for volunteers who would be willing to participate in sessions for professionals. Several indicated they would be happy to do so. Two to five parents from the geographic area close to the meeting site came to each session. Partners in Health had not yet presented Partners in Policy Making for the New York City and Long Island area. Therefore, parents who attended Partners in Policy Making sponsored by the NYS Developmental Disabilities Planning Council presented at the Long Island site.

The other speaker at each site was Dr. Leslie Jameson, director of the Westchester Self-Help Clearinghouse. She has more than a dozen years experience operating a self-help clearinghouse, has provided assistance in starting many groups, and has provided extensive training to professionals on the topic of self-help/mutual support. Dr. Jameson also directed projects to engage culturally diverse populations in self-help/mutual support.

In Batavia, staff of the Niagara County PHC Case Management Program, which has implemented several innovative mutual support programs, described its activities. These included phone pals for special needs children; a parent network; a newsletter for families; a get-together for siblings; and family picnics. Staff also described an energetic, albeit unsuccessful, effort to involve fathers, which generated a lively discussion.

#### CONTENT AREA

In all sites parents began the program by describing the information they learned and skills they developed in empowerment as participants in the program, Partners in Policy Making. While each parent had a unique perspective, common themes were:

understanding the power they had to make changes that would improve the quality of life for themselves and their children; learning how to meet with legislators and other policy makers; learning about existing services and shaping new programs that are needed; the ability to see beyond the needs of their own children and enlarging their vision to include the big picture; and appreciating that they are not alone, and that with other parents they can create a movement for change. In order to convey the richness of these presentations, two of them are included in the Appendix.

The presentation by Dr. Jameson centered on four subjects: 1) the role of public health professionals in self-help/mutual support; 2) confidentiality; 3) various formats for self-help/mutual support and 4) educating supervisors about self-help/mutual support. A brief summary of the ideas discussed follows:

#### 1. Role of Public Health Professionals

Many professionals think that their role is to lead groups. This conference stressed that the role of professionals is to provide assistance so that parents can lead the groups. One of the most important functions for professionals is to refer parents to groups. Other practical ways professionals can assist groups is to provide meeting space at their work sites, provide access to a photocopy machine, send out mailings, design an outreach poster or flyer, circulate recruitment material among clients, and submit announcements of group meetings to local media. Occasionally, groups invite professionals to speak on specific topics at meetings; for the most part, the role of the professional is to provide groups with resources that may not otherwise be available to them.

#### 2. Confidentiality

One of the primary stumbling blocks professionals have to referring families to self-help/mutual support is confidentiality. Experience has shown that confidentiality is not a concern to families; they are eager to meet other families whose children have special health needs. The confidentiality barrier can be overcome by having parents sign a Release of Information Form that allows the professional to give a parent's name to another parent who has a child with a similar problem. Asking parents routinely to sign the form will significantly increase parent-to-parent support.

### 3. Different Self-Help/Mutual Support Formats

Peer support can take place in groups or in one-to-one relationships. Both are equally valid, equally as beneficial and meaningful to participants. Serving as a resource for either type of connection is an equally legitimate use of professional time.

### 4. Professional Involvement in Self-Help/Mutual Support

Professionals need to educate their supervisors as to the validity of self-help/mutual support and the role professionals can play in assisting families with their parent-to-parent networks. Administrators need to understand that the professional's role cannot be measured solely by the number of people who participate in a group meeting, since many other important connections may be operating outside the group process.

#### Number of Attendees:

Physically Handicapped  
Children's Program Staff

44

Self-Help Clearinghouse Staff

6

Central Office Staff  
Dept. of Health

10

Parents

10

Infant Health Assessment Program and  
Early Intervention Program

32

Total Participants = 102

### Ethnocultural Background of Attendees

As part of the evaluation, participants were invited to indicate their ethnocultural background. Of those who responded (60 of 70 evaluations, 86%), the following identification was given:

48 White      9 Black      1 Native American  
2 White Hispanic

### APPROACH

The presenters used a variety of methods to present the material: lecture, discussion among the presenters and between the presenters and the participants, handouts, and small group work. As a culminating activity, each program (PHCP, EI, IHAP) developed a list of steps it could take to increase parent-to-parent support. These are documented in later sections of this report.

In addition, to reinforce the material presented and to provide resources that would be useful in implementing parent-to-parent networks at local sites, participants received the following publications: 1) *New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families*; 2) the report, "Selected Highlights of Research on Effectiveness of Self-Help Groups;" 3) a how-to manual for developing self-help groups, *Tell Me More: Facilitating Small Group Discussions*; 4) a listing of national information and referral programs for common illnesses and disabilities; and 5) order forms for two resources, *The Self-Help Sourcebook: A Comprehensive National Guide to Finding and Forming Mutual Aid Self-Help Groups* and *Organizing and Maintaining Support Groups for Parents of Children with Chronic Illness and Handicapping Conditions*.

Many participants expressed a great deal of interest in engaging fathers in parent-to-parent activities. Staff mailed technical assistance materials on that topic two weeks after the meeting.

### PARTICIPANT EVALUATIONS

Participants evaluated the program by appending numerical values [4 (excellent) to 1 (poor)] to issues such as Program Content,

Method of Presentation, Handouts and Overall Evaluation. Other sections asked participants to provide a narrative answer to questions. The following is a report of ratings of the three different sites and the aggregate for all sites.

| <u>Batavia</u>            | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 3.5               | 4-2          |
| 2. Method of Presentation | 3.5               | 4-2          |
| 3. Handouts               | 3.55              | 4-2          |
| 4. Overall Evaluation     | 3.5               | 4-1          |

| <u>Albany</u>             | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 3.82              | 4-3          |
| 2. Method of Presentation | 3.91              | 4-3          |
| 3. Handouts               | 3.73              | 4-3          |
| 4. Overall Evaluation     | 3.73              | 4-3          |

| <u>Long Island</u>        | <u>Mean Score</u> | <u>Range</u> |
|---------------------------|-------------------|--------------|
| 1. Program Content        | 3.95              | 4-3          |
| 2. Method of Presentation | 4                 | 4            |
| 3. Handouts               | 3.85              | 4-2          |
| 4. Overall Evaluation     | 3.95              | 4-2          |

| <u>Aggregate of Three Sites</u> | <u>Mean Score</u> |
|---------------------------------|-------------------|
| 1. Program Content              | 3.76              |
| 2. Method of Presentation       | 3.77              |
| 3. Handouts                     | 3.71              |
| 4. Overall Evaluation           | 3.73              |

**Best thing about the session:**

There was unanimous agreement that hearing the parents' perspective on services and the system was the best part of the session. Respondents also appreciated the opportunity to exchange ideas with their colleagues. Several people commented on the practicality of the information they received.



**Ways session could have been improved:**

More than 80 percent of the respondents did not reply to this question. Three percent said the session needed no improvements.

Three had complaints about the physical setting, e.g., meeting all day in a room without windows, and a noisy air conditioner. Two participants felt that the parents invited should have been more culturally diverse.

**Did you learn of methods for utilizing self-help/mutual support that are needed or missing in your program?**

51 yes 1 no 6 no response

By far the greatest response to this question (n= 21) was learning that parent support groups should be led by parents, not professionals. Other items mentioned were:

- ☐ Support can be provided by one-to-one contact, not just groups (n=7);
- ☐ Developing a newsletter as a form of support (n=5);
- ☐ Developing a phone network for children (n=4);
- ☐ Distributing how-to material to parents who want to start a group (n=2);
- ☐ How to use a self-help clearinghouse (n=2);
- ☐ How to start a group (n=2);
- ☐ List of 800 numbers (n=2);
- ☐ Ways professionals can support existing groups (n=1); and
- ☐ Developing child-to-child pen pals (n=1).

**Based on this session, are there applications of parent empowerment that you intend to use in your professional practice?**

56 yes 0 no 10 no response

Many respondents left this area blank; several referred the evaluator to the previous question, probably indicating that they would apply information listed above.



Specific applications that were listed include:

- ☐ Will encourage parents to be in charge of groups (n=6);
- ☐ Will encourage more parent-to-parent contacts (n=5);
- ☐ Will start a newsletter (n=2);
- ☐ Will start a parent advisory board (n=2);
- ☐ Will encourage parents to practice advocacy skills (n=4);

Other ideas suggested by one person each were: making office space available to groups; connecting parents on a one-to-one basis, not just in groups; giving information to parents who want to start groups; developing a respite program of volunteer parents; developing a child-to-child pen pal program; linking parents who have children with dissimilar as well as similar concerns; and applying new interpretation of support groups.

#### General comments:

Eighty percent of the respondents made no comment. Those that did comment were very positive. Participants said:

- "Very informative."
- "Best one yet."
- "Interesting and done professionally."
- "Should have unempowered parents meet with empowered parents as in a . . . . parents fair."

#### COUNTY WORK PLANS

As a final activity, each county staff developed a plan for several steps they could take to increase parent-to-parent support. In most counties, all personnel from the same county developed the plan. In a few instances, individual programs developed separate plans; this distinction is noted where pertinent.

Staff who attended from each county are identified on the registration lists for each site; they are located in the Appendix.

## **Albany County**

### *Physically Handicapped Children's Case Management Program*

Will initiate a periodic newsletter to connect parents and will consider publishing a "Hunting List," which alerts parents to connections requested by other parents. Will canvass community for free meeting places and publish list.

Will develop a form that asks, "Would you be interested in a support group or talking to another parent who has a similar situation?"

## **Cattaraugus County**

- Work with county self-help clearinghouse and Rehabilitation Center to support existing groups and enhance the development of groups for other concerns.

## **Chautauqua County (See Schuyler County)**

## **Erie County**

- Continue current efforts to connect families in parent-to-parent support.

## **Herkimer County**

- In PHCP Newsletter, publish a list of families who are willing to be contacts for other families.
- Canvass community for free meeting places and publish list.
- Develop a group around one disability.
  - a. Select the disability.
  - b. Develop and use a form so that confidentiality is not a barrier to referral.
  - c. Get parents connected to each other.
  - d. Encourage ride sharing to meetings.

## **Monroe County**

In all activities, work across department of health programs, such as Early Intervention, PHCP, and so forth.

- Start parent to parent group and a newsletter.
- Canvas community to locate existing groups.
- Offer practical assistance to groups, such as copying, and so forth.
- Implement one-to-one connections.
- Considering starting a newsletter.

## **Nassau County:**

### *Physically Handicapped Children's Case Management Program*

- Introduce parents with similar concerns to each other.

## **New York City**

- Develop parent to parent support through telephone network.

## **Niagara County:**

- Will attempt to turn control of existing parent group to the parents.
- Continue to offer workshops for parents, and will video tape them for parents who cannot be present, and for other agencies.

## **Onondaga County:**

- Encourage parent-led group for the hearing impaired.
- Work on connecting siblings to each other.

## **Ontario County (See Schuyler County)**

## **Orleans County (See Yates County)**

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### **Saratoga County**

- Start a newsletter.
- Offer county office building as meeting place.
- Use monthly news release developed by public health nurses to inquire about parents who may want a support group or who wish to talk to another parent.
- Use other agencies to get out publicity, for example, print notice in school menus.

### **Schuyler, Wayne, Ontario, Chautauqua Counties**

- Identify existing groups
- Encourage interagency cooperation for development of parent-to-parent support.

### **Seneca County**

- Use established network as a base for developing other groups.
- Implement within PHCP some ideas discussed, such as:
- Parent to Parent Support
- Child to Child Support

### **Suffolk County:**

#### *Bureau of Public Health Nursing*

- Refer families to existing groups.
- Develop one-to-one connections among families within Service Coordination Program.

#### *Physically Handicapped Children's Case Management Program*

- Apply lessons learned to develop groups.

Both programs in Suffolk County will make sure they know about existing services so they don't duplicate efforts.

### **Tompkins County**

#### *Physically Handicapped Children's Case Management Program*

- Parent Advocacy Meeting Speaker - Jeff Stoughton STARN
- Newsletter - first issue July 1992
- Sibling Support Group is in the planning stage under the leadership of a parent; sibling is involved in planning.

### **Ulster County**

- Put the information on support networks in reference file of public library.
- Use other referral sources to give information to parents, especially pediatricians.
- Alert school nurses and school counselors to parent activities.
- Economic support to help parents attend.

### **Wyoming County**

- Network among three providers to determine if there is a possibility for a group.

### **Yates County:**

- Initiate a phone pal system; will need to work on problem of long distance calls.
- Assist parents of children who have asthma to organize a group. Parents have expressed an interest. Will see how this group develops and will involve other chronic diseases, if possible.

### **Wayne County (See Schuyler County)**

### One County's Progress

On November 5, 1992, Partners in Health staff conducted a telephone interview with the Suffolk County Physical Handicapped Children's Case Management Program in order to evaluate the progress that has been made on working with parents. The Director of the Case Management Program was enthusiastic and pleased with activities that had occurred to date. These are:

#### 1. Development of a parent-led diabetic support group.

CMP coordinated with the local hospital, which provides the majority of services to diabetic children. Together they organized a support group for families whose children have diabetes. Three meetings have been conducted. Approximately 85 people attended the last session.

This group was planned prior to the training session, but as a result of information presented there, the professionals encouraged parents to lead the group with case managers and the Physically Handicapped Children's Program staff to be there to provide backup support with such items as clerical and computer assistance. A nucleus of five families has accepted the organizational challenge of formally organizing and electing temporary officers. In the meantime, a father has successfully run the last two meetings and organized 30 parents to attend the Juvenile Diabetes Foundation (JDF) program that was held in neighboring Nassau County. The group also had tickets for the Ice Capades in November.

One mother has been working to connect children on a one-to-one basis and successfully made a match between two eight-year-old girls who live near each other and never interacted with another child with diabetes.

Families from the group are being trained by the American Diabetes Association to act as volunteers to visit newly diagnosed children and families, either at the time of hospitalization or immediately thereafter.

#### 2. Involving parents on advisory committees.



CMP invited two parents to be on its advisory board. They also have recommended one of the parent panelists to serve on the county's Early Intervention Advisory Committee.

### 3. Involving parents in professional development.

Several parents of chronically ill children were part of a panel presentation at SUNY School of Nursing. The topic of parent-professional communication was discussed with parents making nurses aware of positive as well as negative communications they had experienced since the birth of their children. The presentation will be repeated on March 16, 1993, at the Suffolk Coalition for Parents and Children, a county-wide group interested in issues related to children.

### RECOMMENDATIONS FOR FOLLOW-UP

This report documents a training program that was well received and positive action steps that can be taken by many counties. A follow-up survey would be a useful tool for determining what counties were able to accomplish. In addition, it would be beneficial to sponsor follow-up sessions that build on the material learned thus far and reinforce positive application. In addition, with time, the Bureau of Child and Adolescent Health will learn more about issues regarding parent-to-parent support for culturally diverse families who have children with special needs. This new knowledge would enrich the current body of knowledge and be helpful to local programs.

### REFERENCES

Association for the Care of Children's Health. *Family-Centered Care for Children with Special Health Care Needs*. (Washington, DC: Association for the Care of Children's Health, 1987).

Interstudy. *Executive Summary: Report to the Steering Committee for the Surgeon General's Workshop on Self-Help and Public Health*. (Evanston, IL: Self-Help Center, 1987).

## **BUDGET**

### **Part H**

|              |                  |
|--------------|------------------|
| Quality Inn  | \$ 302.00        |
| Holiday Inn  | \$ 442.00        |
| Treadway Inn | <u>\$ 461.00</u> |
|              | \$1,205.00       |

|                                          |                   |
|------------------------------------------|-------------------|
| Consultant Fees<br>Parents<br>12 @ \$150 | \$1,800.00        |
| <u>Subtotal</u>                          | <u>\$3,005.00</u> |

### **Partners in Health**

|                   |                   |
|-------------------|-------------------|
| Consultant Fee    | \$1,080.00        |
| Staff Travel      | \$ 913.00         |
| Consultant Travel | \$ 564.00         |
| <u>Subtotal</u>   | <u>\$2,557.00</u> |

|              |                          |
|--------------|--------------------------|
| <b>TOTAL</b> | <b><u>\$5,562.00</u></b> |
|--------------|--------------------------|

For additional information, contact:

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## APPENDIX A

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Presentation by Linda Carroll  
June 12, 1992

I'm Linda Carroll. I have two children, Jeff who is 11 and Jenny who is 6. Jenny has a rare chromosome abnormality and is developmentally delayed.

In order to tell you why I was interested in Partners in Policy Making, I have to tell you what it's been like since learning of Jenny's disability.

I had a normal delivery and had what we thought was a normal, healthy baby. The only minor problem was jaundice which caused her to remain at the hospital for four extra days.

After that, everything was going along fine until at four months a heart murmur was discovered. When she was six months old, I began to feel something wasn't right. Jenny wasn't reaching the developmental milestones. At eight or nine months a cardiac catheterization was performed (which was very scary). We were lucky, she had some minor heart defects, but nothing serious enough to cause the delays that were becoming more evident.

At about this time we also started seeing a neurologist who ran a series of tests to try to determine the cause of Jenny's problems. All the tests were negative, but one, unfortunately. The chromosome analysis. This was devastating news. We didn't know what to do, we felt so alone. We felt guilt, fear, helplessness, loss and sadness, and I felt Jenny was the only handicapped child in the world. Everywhere I looked there were normal, healthy children. Family, friends and strangers in the supermarket -- all with normal children. Our dreams were shattered. From that moment on, our lives would be changed, and we had to find a way to accept and embrace this new life.

There were two things that began to turn things around for us and help us begin to come to terms with Jenny's disability. The first was meeting Dr. Janet Fischel, a developmental psychologist at Stony Brook University Hospital. She was very supportive and told us about early intervention programs. She has followed Jenny since

that time and continues to support and guide us. And the second was starting in our first support group at Just Kids, the preschool that Jenny attended.

In the real world, Jenny was different from other children. But here in the group, Jenny fit in. I could talk about Jenny and feel comfortable. It was like a weight had been lifted. We talked about our feelings, our children's rights, their education, their future, whatever we needed to talk about. And I also realized there was so much I needed to learn. I felt inadequate as a parent for Jenny. I knew how to nurture my son, but Jenny's needs were so different. There were medical, educational, physical, social, and family needs. There was a lot of pressure on us. The support of the other parents helped enormously and we began to see a new happy, but different life. The teachers and therapists were another great source of help. They taught me how to appreciate Jenny's strengths and to overcome her weaknesses.

One day I received a flyer from Jenny's school about attending an important meeting about a change in pre-school programs. At the meeting, I sat and listened while they talked about legislation, bill number so and so, parent choice, PL-142, PL 99-457. I had no idea what they were talking about, but I knew I had better find out. So I attended every meeting they had so that I could begin to understand the legislative process and what it would mean for Jenny's education. I began to realize that to give Jenny what she needed would take more than just taking care of her everyday needs. Even though she was only three, I had to start thinking about her future.

We joined various organizations so that we could get more and more information about the disabled. I began to see that there were many issues that would have to be addressed in order for Jenny to have a successful future. I could see that parents needed to have choices and to make informed decisions about their children. And in order to do that parents needed to have lots of information. The more the better.

With the support of Just Kids and our growing involvement in the fight for maintaining services through the legislative process, my husband and I were able to start a parent organization at the school. We wanted an organization that would support parents and get information to them so they would be able to make informed choices for their children. We started by bringing in guest speakers to

discuss a variety of relevant topics. We added a newsletter that we publish several times a year. Some of the articles we included are about the parent organization, articles about what some of our parents are doing to advocate for their children, legislative information, and local organizations and services that may be helpful. We also work with the staff to find ways to get parents more involved with the education program.

I also started and coordinated a parent support network whereby parents can call a more experienced mom if they need information or have a problem or just need to talk to someone who understands. We do this through the social work and psychology departments at the school.

As I mentioned, we joined various organizations. One of those organizations was the Family Support Network. This was made up of parents of handicapped children throughout Suffolk County. They offered training sessions in policy making and advocacy, information on support services, as well as many other areas of importance. We were then able to bring this information back to our parents at Just Kids. Through our involvement in this organization, we received an application to attend Partners in Policy Making. We felt this was an opportunity we couldn't pass up. We had found through our earlier experiences of lobbying for legislation that there was a need for someone to take a leadership role and to be part of a larger group to be more effective. When I read the application, one paragraph convinced me that I wanted and needed to attend this training. It read, "This leadership training program is specifically designed to improve the skills of participants -- by giving them the tools that will help them become more effective advocates in improving the quality of life for people with developmental disabilities." So my husband and I filled out the application and hoped we would be selected, and we were.

We were looking for the opportunity to gain new knowledge and network with parents. I knew that the parents that would be attending would be those who truly wanted to make a difference for children and adults with disabilities. And I knew that we would get the most up-to-date information relevant to the issues surrounding people with disabilities.



There were five training sessions. Each session covered different topics, and we had the opportunity to hear from leaders in the field working for the disabled.

At the first session, Allen Bergman, the Deputy Director of Government Activities Office, United Cerebral Palsy Association, spoke. He talked about the shifting of society's views towards the disabled from the 1850's to the present and showed us how much further we still had to go and what we could hope for in the future. He showed us that we had the power to make those changes.

At our next session, the legislative process was explained by Robert Boehler from the New York State Office of Advocate for the Disabled. Through role play we were able to practice some of the skills necessary to lobby effectively. Assemblyman Steve Sanders, who has sponsored many bills for the disabled, then addressed the group.

Our next session addressed the problems of the health care and health insurance systems. Bob Griss, Senior Health Policy Analyst of the National United Cerebral Palsy Association in Washington, D.C., feels that health care is a right for everyone, and our national policy has to change to reflect this.

What personally interested me the most was the topic of our next speaker, Lou Brown, from the University of Wisconsin, "Inclusion in Today's Society." He told us of the Madison, Wisconsin, School District's move towards inclusion of all children with disabilities. The program had been very successful. He pointed out the need to integrate children from the start, if they are to be accepted in society as adults.

At the last session, Colleen Weick from the Minnesota Governor's Planning Council talked of leadership and vision. She envisions a society where we focus on the strengths and gifts of people with disabilities rather than their weaknesses. She also assigned each of us the task of finding something in our community that if changed would help people with disabilities. And to use the skills we had learned to make that change.

Through all five sessions we also worked in small groups on case studies in our own area of interest. This gave us an opportunity to brainstorm and share views on the problem we were given to

resolve. It helped us to see different viewpoints and come to a compromise that was satisfactory to all.

What I gained from these training sessions was invaluable. I could see the big picture. I left the training with a feeling of empowerment. A feeling of "I can do it, I can make changes." I now know that just because something has always been done a certain way doesn't mean that it the best way. And if it's not the best way, then it must be changed. Society must be educated to the fact that disabled people are people first. People with feelings, emotions, wants and needs, with the same rights as every citizen.

You may have seen this week in the news that arson was suspected in a fire at a proposed group home in Northport for developmentally disabled adults. Many of the neighbors in the area were opposed to "those people" living in their neighborhood. Disabled people have a right to live and work in this society. What is it that caused people like those in Northport to feel as they do? Is it fear? Lack of knowledge? Misunderstanding? Maybe all of those. Whatever it is, it must be changed.

I think that there is a lot that needs to be changed, and I hope I can be part of making some of the dreams and ideals for the disabled a reality.

*Linda Carroll participated in the Partners in Policy Making sessions sponsored by the New York State Developmental Disabilities Planning Council.*

**Presentation by Monica Harrison**  
**June 12, 1992**

I spent a long time debating with myself on what to say about the "Partners" (Partners in Policy Making) experience. I then realized that I could not fully explain my interest or what made me participate unless I gave you a brief history on my son, my experiences, and what lead me to that point.

I had two beautiful, healthy children ages nine and eight when Kevin was born. Having a newborn eight years later was shock enough, but having a child born with disabilities was something I was in no way prepared for. I didn't even know a family who had a child with problems. The most traumatic event in my other children's lives had been when they had chicken pox or when my eight-year-old needed two stitches.

Then came Kevin. Now Kevin had a rough start at birth -- he was 12 pounds and for all the health care people, no, I did not have diabetes; we just happen to grow them big in my family. He did have a low glucose level and a high respiratory rate; he was also suspected of having Beckwith Syndrome. So Kevin was transferred to a University Hospital where all these things were pretty well counted out with testing. And when his breathing stabilized and his glucose rose to normal levels, he came home.

Then at one month of age he was rushed to surgery for a hernia that required a bowel resection. He was sent home again six days later and things seemed to get normal for my household, until Kevin was about five months old. Something didn't seem right to me. He didn't seem to be progressing as much as I thought he should. I remember feeling foolish checking in books about child development -- after all, Kevin was my third child. I relayed my fears to his pediatrician and he responded that he had noticed a slight lag, but had waited for my lead, and since I was concerned, we started testing. He recommended that we take Kevin to see a neurologist; there he had EEG's, Cat Scans, one or two times testing by the doctor himself. I was very scared and upset. Nothing was showing up abnormal, yet the doctor was telling my husband and me that children like these usually don't go very far or do very much. Children like what? From there he was sent for hearing tests, visual tests, and still we had nothing conclusive. Somewhere in the back of

my mind I kept hearing the doctor say, "Children like these" don't do very much, and I thought maybe not very much in his world, but in the realm of my family Kevin does plenty.

Granted, Kevin is two years old now and still he cannot sit, talk or crawl. He does have a limited visual attention span. He doesn't yet use his hands to reach or grasp things, and he is not always responsive to sound, but he smiles and laughs better than anyone I have ever met. (Sure I'm prejudiced, I'm his mother. But don't take my word for it, ask his dad, sister or brother and they will say the same thing.)

Somewhere in the midst of all the testing, Kevin started in an Early Intervention Program where he received maximum therapies at home. And somehow, with the help and a little pushing from his teacher, I ended up at a support group. It was through his school and ran for six weeks. That may seem long but when it was all over I asked myself, "Where do we go from here?" I had heard very heartbreaking stories about lack of family support, family unacceptance and attitudes from outsiders that are beyond belief. I knew something had to be done to help these mothers. I was pretty lucky I had support from a loving family and friends but others didn't.

So I decided to start my own support group, "Special Moms of Special Children." I got a room, started advertising and was off to a good start. As more and more moms phoned, I started to hear the same complaints and problems over and over again -- we were not being given the help we so desperately needed, information was scarce and almost unattainable, we were being told what we should do but were not being asked what we felt should be done. Goals and strategies were being set up for our children, but were they our goals? I started to feel a real injustice was going on toward our children and toward us.

Then out of the clear blue something terrific happened. I was given a business card by someone I know and was told this woman said to call her if I needed any help. I made the call because we as a group decided we were ready for a guest speaker. I called up and that's when Margaret Sampson came into my life. You may or may not know her, but her reputation speaks for itself. Margaret came into our meeting and spoke to us about what was available for our children. Then she reeled off a list of agencies or should I say a list

of initials like, DDPC, UCP, SSI, DOH. The list was overwhelming, and I sat in total shock as to how little I really knew.

Then and there I made a promise to myself and my son that I would do anything I had to, to learn what I could. I would write away for any resources available. If I heard of a group or agency, I would request the information available. I began to share with my group what I was learning, and they in turn would share the knowledge they were acquiring. One day in the mail came an application for "Partners in Policy Making." It had Margaret Sampson's name on it so I decided I had to try to be picked to attend. This I knew would help not only my son, but others that I could reach. I would learn the right way to deal with a system that had been established long before I entered the picture.

From the beginning, the Partners experience was more that I had hoped for. There were parents from both ends of the Island and parents with children of all ages. There were people with disabilities of their own and professionals highly regarded in their field, people from the Developmental Disabilities Planning Council, New York State Department of Health, Suffolk County Office of Handicapped Services -- the list goes on and on. There were people whom I never would have gotten the opportunity to talk to, yet they were listening to my opinions and thoughts on certain subjects. I was both impressed and intimidated at first by the power in that group -- a group to which I now belonged. One thing that struck me was that no matter what our differences or diversities, we all shared a common goal -- someone special in our lives needed our help! The experiences we gained from one another as parents would have been enough to fulfill what I took home from the Partners meetings. I saw parents telling other parents how they had accessed services; we exchanged the numbers of doctors who had been most supportive and helpful; we debated issues; we confided in one another; and as time went by, we formed friendships.

We started with a fantastic speaker, Alan Bergman, from United Cerebral Palsy, who spoke on Family Support. He asked us what we would like to see changed for the disabled community by the year 2001. Of course, we had no problem coming up with answers. We wanted inclusion, community acceptance, more of an active, participating role in all aspects of our children's treatment, and easy access to all services that are available. Then he sent the



message -- these things can occur through active advocacy efforts. He put the power in our hands. We were only a small group of around 50 people, but we were only a fraction of what we could be. Maybe together we could change things. Next, we learned advocacy skills from Robert Boehlert who is from the Office of Advocate for the Disabled. A New York City Assemblyman, Steven Sanders, gave us pointers on dealing with officials. We listened and learned about the health care system, focused on leadership and vision, talked about inclusion with a man from a place in Wisconsin where it is not a dream, but a reality.

We were given assignments -- we had to write to our state and local officials and let them know who we were. There were group projects in which we researched extensively such things as respite, our power at an IEP or CSE meeting, transition and planning for the future. There were reports on aging and family support.

Month by month you could see the difference in yourself and the others. The more we learned the more we wanted. We were changing and were less afraid to speak up, or for, what we believed. We asked more questions and we demanded more answers. We were truly becoming "Partners" and we knew our power.

At the last meeting, we were asked to try to give something back to the Partners. Something that could maybe be easily attained, but something that would make a difference for the disabled community. We divided into small groups of two or three and we're expected to report back in September when we meet for our reunion. The room was filled with visions that ranged from a wheelchair swing in the park, to a ramp from the edge of the beach all the way to the water. Others wanted to make a movie theater accessible. As I sat there, I could see the change from when we had started. If they had asked us the same thing in the beginning, our goals would have been a lot less.

I took so much from the whole experience. I have more confidence for the future. I feel much more in control of my situation. I am not afraid now that I have the knowledge to use my power and to tell everyone I deal with that they have it too. My standing before you today is a direct result of what I have gained. Sure, I'm scared to death. Why did I do it? Because I was asked and unless we as parents tell you how we feel, how are we to change things?



In conclusion, let me tell you that I consider myself one of the lucky ones. My son is only two years old, so the feeling that I can help to make a difference came early. We have a lifetime to try to make things different so his world is accepting and fair. There were others whose children are now grown men and women. That they are still willing and able to fight for the rights of others gives me the hope and strength I need for the long ride ahead. And if you were ever to meet my son, Kevin, you would know why I will never concede the battle. Thank you

*Monica Harrison participated in the Partners in Policy Making sessions sponsored by New York State Developmental Disabilities Planning Council.*

## Appendix B

Empowering Families Through Self-Help/Mutual Support  
Albany  
June 5, 1992

Pam Cardinal  
RR#1, Box 89  
Clinton, NY 13323  
315-853-7170

Marie C. O'Malley  
152 Old Route 17K  
Montgomery, NY 12549  
914-361-3306

Eileen Tracy  
P.O. Box 318  
Morris, NY 13808  
607-263-2468

Albany County Health Department  
P.O. Box 678  
Albany, NY 12201-0678  
518-477-4615  
Linda Conway  
Terri Newell

Judy Mercurio  
Essex County Public Health  
100 Court Street  
Elizabethtown, NY 12932  
518-873-6301 x244

Fulton County Nursing Service  
P.O. Box 415  
Johnstown, NY 12905  
518-762-0720  
Pamela Hart-Stanley  
Charlotte Loccatelli  
Chris Stegel

Herkimer County Public Health  
Child Health  
Financial Assistance  
257 North Main Street  
Herkimer, NY 13350  
315-867-1183  
Arlene Brouillette  
Nancy Crewell  
Lou Ann Fiore  
Linda Maida  
Jean Wallin

NYS Dept of Health  
Bureau of Child & Adolescent Health  
ESP Corning Tower Room 281  
Albany, NY 12237-0618  
518-474-2001  
Thomas Carter  
Mary Huber  
Nancy Kehoe

Rockland County Health Dept  
Bldg. D, Sanatorium Road  
Pomona, NY 10977  
914-354-0200 x2626  
Harriet Bleacher  
Maddy Levine  
Esther Spiegel

Saratoga County Public Health  
Nursing Service  
31 Woodlawn Avenue  
Saratoga Springs, NY 12866  
518-584-7460  
Kay Seabury  
Gail Shea

Karen Wakeman  
Ulster County Health Dept.  
300 Flatbush Avenue  
Kingston, NY 12401  
914-338-9130

Victoria Holley  
Washington County Public Health Svc  
Lower Main Street  
Hudson Falls, NY 12837  
800-624-4221

Westchester Self-Help Clearinghouse  
Westchester Jewish Community Svcs  
456 North Street  
White Plains, NY 10605  
914-949-6301  
Leslie Jameson

The conference is jointly sponsored by:  
Federal Part H (PL 102-119) Program for Infants and Toddlers  
with Disabilities and Their Families and  
by Partners in Health: Self-Help/Mutual Support for  
Culturally Diverse Children with Special Health Needs  
and Their Families, Project #MCJ367034919 from the  
Maternal and Child Health Program  
(Title V, Social Security Act)  
Health Resources and Services Administration,  
Department of Health and Human Services.

Empowering Families Through Self-Help/Mutual Support

Batavia

June 9, 1992

Jennifer Huff  
RD#1 Box 504  
Gowanda, NY 14070  
716-532-4624

Susan Mahserjian-Smith  
190 Oak Street  
Batavia, NY 14020  
716-343-1670

Cattaraugus County Health Dept  
1701 Lincoln Avenue  
Olean, NY 14760  
716-373-8050 x383  
Connie Kramer  
Debbie Miller

Chautauqua County Health Dept  
Hall R. Clothier Bldg  
Mayville, NY 14757  
716-753-4262  
Darleen Barney  
Jude Shanahan

Department of Youth Services  
134 West Eagle Street  
Buffalo, NY 14202  
716-858-8944  
Janet DeLoach  
Mike Kubik

Erie County Dept of Health  
95 Franklin Street  
Rath Bldg Room 950  
Buffalo, NY 14202  
716-858-7685 ~~88092~~  
Lila Diederich  
Bob Illig  
Pat Paterniti  
Penny Purebski  
Paul Shriver  
Gary Wolfe

Genesee County Dept of Health  
County Bldg 2  
3837 West Main Road  
Batavia, NY 14020  
716-344-2580  
Margaret Dempsey  
Cecilia Lyons

Monroe County Health Dept.  
111 Westfall Road, Caller 632  
Rochester, NY 14692  
716-274-6174  
Sandy Berg  
Kathleen Conroy  
Donna Lowry  
Patricia Sorbadhikari  
Lisa Westin

NYS Dept of Health  
Bureau of Child & Adolescent Health  
ESP Corning Tower Room 281  
Albany, NY 12237-0618  
518-474-2001  
Nina Daratsos  
Mary Huber

Cathy Stein  
New York State Dept of Health  
Western Regional Office  
584 Delaware Avenue  
Buffalo, NY 14202-1295  
716-847-4531

Niagara County Health Dept  
Physically Hand Childrens Program  
Main Post Office Box 428  
10th & East Falls Street  
Niagara Falls, NY 14302  
716-284-3132  
Carol Augustell  
Angie Bickett  
Lisa Chester  
Mary Ann Feely  
Angela Gedeon  
Tina Marshall  
Ola McClendon  
Sharon McLaughlin  
Tammy Roberts  
Carol Schrader  
Norann Szczesny

Niagara County Self-Help  
Clearinghouse  
MHA in Niagara  
151 East Avenue  
Lockport, NY 14094  
716-433-3780  
Terri Seidel  
Lynne Turner  
Liz Williams



Onondaga County Health Dept  
Physically Handicapped Childrens  
Program  
375 W. Onondaga Street  
Syracuse, NY 13202  
315-435-3230  
Irene Blakeslee  
Michelle Vasquez

Mary Ann O'Brien, RN  
Ontario County Public Health  
3907 County Road #46  
Canandaigua, NY 14424  
716-396-4358

Orleans County Health Dept  
14012 Rte 31  
Albion, NY 14411  
716-589-7004 x377  
Christine A. Covell  
Evilene Kubatek  
Gail Pettit

Gretchen Jackson  
STARN  
181 West Buffalo Street  
Warsaw, NY 14569  
716-786-8590

Marcia Kasprzyk  
Schuyler County Home Health Agency  
105 9th Street  
Watkins Glen, NY 14891  
607-535-2704

Seneca County Dept of Health  
31 Thurber Drive  
Waterloo, NY 13165  
315-539-9294  
Rosemary Barto  
Sister Mary Christoper

Tompkins County Health Dept  
PHCP, IHAP, EIP  
401 Dates Drive  
Ithaca, NY 14850  
607-274-6645  
Carol Holland  
Barbara Ozminkowski  
Wendy Woodams

Pamela Taylor  
Wayne County Public Health  
Early Intervention Service  
7320 Route 31  
Lyons, NY 14489  
315-946-5749

Leslie Jameson  
Westchester Self-Help Clearinghouse  
Westchester Jewish Community Svcs  
456 North Street  
White Plains, NY 10605  
914-949-6301

Wyoming County Health Dept.  
338 N. Main Street  
Warsaw, NY 14569  
716-786-8890  
Cathy Montgomery  
Pat Prinz, RN

Mary Griffiths  
Yates County Public Health  
Nursing Service  
431 Liberty Street  
Penn Yan, NY 14527  
315-536-5160

The conference is jointly sponsored by:  
Federal Part H (PL 102-119) Program for Infants and Toddlers  
with Disabilities and Their Families and  
by Partners in Health: Self-Help/Mutual Support for  
Culturally Diverse Children with Special Health Needs  
and Their Families, Project #MCJ367034919 from the  
Maternal and Child Health Program  
(Title V, Social Security Act)  
Health Resources and Services Administration,  
Department of Health and Human Services.

Empowering Families Through Self-Help/Mutual Support  
Long Island  
June 12, 1992

BFSN  
111 Livingston Street, Room 2022  
Brooklyn, NY 11201  
718-643-7630  
Nathaniel Brunson  
Lynn Christopher  
Denise Desrolullers  
Emily Gordon

Long Island Self-Help Clearinghouse  
New York Institute of Technology  
Cottage B  
Central Islip, NY 11722  
516-348-3030  
Cheryl Hamilton  
Pat Verdino

NYS Dept of Health  
Bureau of Child & Adolescent Health  
ESP Corning Tower Room 287  
Albany, NY 12237-0618  
518-474-2001  
Nina Daratsos  
Mary Huber

Cecilia Castillo  
Nassau County Dept of Health  
240 Old Country Road  
Mineola, NY 11501  
516-535-3624

Office of Public Health  
NYS Dept of Health  
5 Penn Plaza  
New York, NY 10001-1803  
212-613-2446  
Nancy Bradford  
Cheryl Hunter-Grant  
Agnes M. Larson

Suffolk Co Dept of Health Svcs  
225 Rabro Drive East  
Hauppauge, NY 11788  
516-853-3069  
Mary Lou Boyle  
Judy Marcus  
Barbara Metrick  
Sandra Siegel  
Jane Turner

Suffolk County Dept of Health Svcs  
PHCP  
North Brookhaven Center  
3600 Route  
Coram, NY 11727-4116  
516-854-2224  
Angie Kohlepp  
Lorraine Rickman  
Christine Small

Leslie Jameson  
Westchester Self-Help Clearinghouse  
Westchester Jewish Community Svcs  
456 North Street  
White Plains, NY 10605  
914-949-6301

The conference is jointly sponsored by:  
Federal Part H (PL 102-119) Program for Infants and Toddlers  
with Disabilities and Their Families and  
by Partners in Health: Self-Help/Mutual Support for  
Culturally Diverse Children with Special Health Needs  
and Their Families, Project #MCJ367034919 from the  
Maternal and Child Health Program  
(Title V, Social Security Act)  
Health Resources and Services Administration,  
Department of Health and Human Services.

## Appendix C



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower

The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Lorna McBarrette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kasy  
Executive Deputy Director

## SAVE THESE DATES

March 17, 1992

Dear Colleague:

It is our pleasure to announce a forthcoming workshop for the PHC Case Management Programs, "Empowering Families through Self-Help/Mutual Support." Early Intervention Service Coordinators are also welcome to attend.

The following topics will be addressed:

- 1) **Partners in Policy Making.** More than 150 families statewide who have children with chronic illnesses or physical disabilities will be participating in this program. Its goal is to provide them with skills to become advocates on behalf of their children and themselves. Conference staff will describe the program and discuss ways in which the families may be working with local case management programs as they practice advocacy skills.
- 2) **New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families.**  
A review of the Directory, its uses and potential modifications will be discussed.
- 3) **Self-Help/Mutual Support for Families Whose Children Have Special Health Care Needs.** The importance of self-help/mutual support, the professional's role in support groups, and engaging culturally diverse families in self-help/mutual support are a few of the topics that will be covered.



The program will be held in three areas of the state in order to accommodate all sites. Please save the following dates:

- |                     |                 |
|---------------------|-----------------|
| • Albany, New York  | Friday, June 5  |
| • Batavia, New York | Tuesday, June 9 |
| • Long Island       | Friday, June 12 |

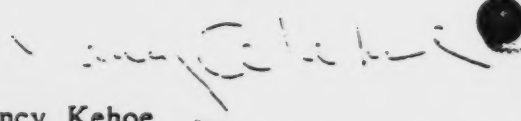
The times for the workshops are:

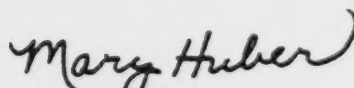
|                  |                    |
|------------------|--------------------|
| Registration     | 9:30 am - 10:00 am |
| Training         | 10:00 am - 4:00 pm |
| Lunch (Provided) | Noon               |

Registration and maps will be mailed approximately one month prior to the workshops.

We look forward to being with you and sharing this important information.

Sincerely,

  
Nancy Kehoe  
PHC Program Administrator

  
Mary Huber  
Director  
"Partners in Health"

cc: Regional Maternal and Child Health Nurses  
Regional Early Intervention Nurses  
PHC Case Management Coordinators  
County Early Intervention Officials  
"Partners in Health" Self-Help Clearinghouses  
Olivia Smith-Blackwell, M.D.  
Goldie Watkins



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower

The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Lorna McBarnette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

April 27, 1992

Dear Colleague:

Enclosed are the registration forms and directions for the regional conferences, "Empowering Families through Self-Help/Mutual Support". The programs are part of the ongoing in-service training for PHC case managers. Early Intervention Coordinators are also welcome to attend. The purpose of the conference is to show how case managers can utilize parent support groups as another way of achieving family centered care.

In addition, recent workshops to provide skills in policy making to families who have children with special health needs will be described. Many of the 150 families statewide who have participated in Partners in Policy Making also utilize case management services and may approach your programs as they practice what they learned. The conferences will prepare you to work with families in their policy making endeavors. Special emphasis throughout the conferences will be the engagement of culturally diverse families in these activities.

A brief needs assessment that is intended to guide our discussion is included. Please make copies and distribute them to staff and return with the enclosed registration form.

We look forward to seeing you.

Sincerely,

Nancy Kehoe  
PHC Program Administrator

*Mary Huber*  
Mary Huber  
Director  
"Partners in Health"

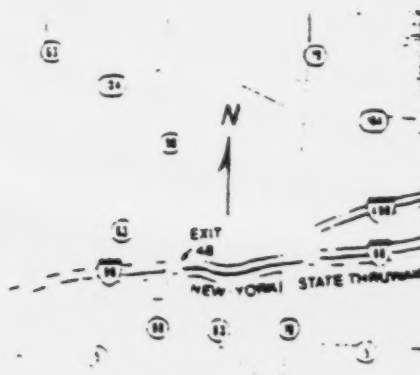
cc: Regional Maternal and Child Health Nurses  
Regional Early Intervention Nurses  
PHC Case Management Coordinators  
County Early Intervention Officials  
"Partners in Health" Self-Help Clearinghouses

a:MH07

Tuesday, June 9

Treadway Batavia Inn  
8204 Park Road  
Batavia, NY 14020  
716-343-1000

Directions: Opposite Thruway Exit 48 at Route 98

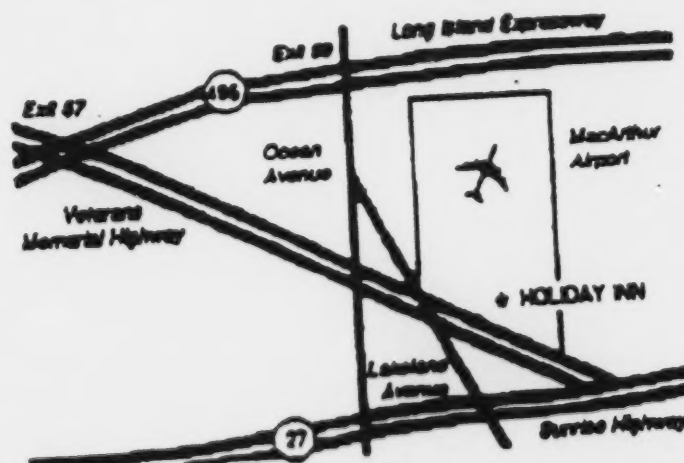


Friday, June 12

Holiday Inn  
3845 Veteran's Memorial Highway  
Ronkonkoma, NY 11779  
516-585-9500

Directions: Train from New York City. From Penn Station, go to Ronkonkoma Station. When you arrive, call the hotel, which is about two minutes away. A van from the Holiday Inn will meet you.

From New York City: LIE (I-495) Exit 57, go 2 lights to Veteran's Memorial Highway. Turn right and go 4 miles to the Holiday Inn. From Eastern Long Island: LIE (I-495) Exit 59 to Ocean Ave., turn left and proceed to Lakeland Avenue, then bear left to Veteran's Memorial Highway. Turn left and into the Holiday's Inn.



## NEEDS ASSESSMENT

### Regional Training Conferences Empowering Families through Self-Help/Mutual Support

#### I. New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families

1. Have you used the directory? \_\_\_\_ Yes \_\_\_\_ No

2. If you have not used the directory, please explain the reason.

---

---

---

3. If you have used the directory, please check the ways you have used it:

- \_\_\_\_ I called a network contact person for information about the network.
- \_\_\_\_ I contacted some of the resources listed in the back of the directory.
- \_\_\_\_ I referred a parent to one of the networks.
- \_\_\_\_ I facilitate a network and called another network to exchange information.
- \_\_\_\_ Other. Please explain. \_\_\_\_\_

---

---

4. Please list other information that would be useful in the directory.

---

---

---

---

5. Please indicate any general reaction to the directory you would like to share.

---

---

---

---

II. Self-Help/Mutual Support for Families Who Have Children with Special Health Needs

1. Have you connected families to mutual support networks?

\_\_\_ Yes      \_\_\_ No

2. If no, please indicate why you do not do so.

---

---

---

---

3. Please indicate below any issues about self-help/mutual support you would like to discuss in the upcoming meeting.

---

---

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Thank you for completing this form. Please return it with the registration to:

Mary Huber  
NYS Department of Health  
Corning Tower Bldg., Room 208  
Empire State Plaza  
Albany, NY 12237

MH067

210

## Appendix D



# AGENDA

## Empowering Families through Self-Help/Mutual Support

- 10:00 am Welcome and Overview of the Day  
Participants' Interests
- 10:30 am "Partners in Policy Making"  
Panel Presentation by Parent Graduates  
Discussion
- 11:30 am *New York State Directory of Self-Help/Mutual  
Support for Children with Special Health Needs and  
Their Families*  
Review and Discussion  
*New York State Parent Resource Directory*  
Review and Discussion
- 12:30 pm Lunch
- 1:30 pm Self-Help/Mutual Support for Children with Special  
Health Needs  
Presenter: Leslie Jameson, Ph.D.  
Westchester Self-Help Clearinghouse
- 3:45 pm Wrap-up and Evaluation

## Appendix E

### Session Evaluation

Empowering Families through Self-Help/Mutual Support

Please rate each of the following:

|                                  | Excellent | Good | Fair | Poor |
|----------------------------------|-----------|------|------|------|
| 1. Program Content               | 1         | 2    | 3    | 4    |
| 2. Method of Presentation        | 1         | 2    | 3    | 4    |
| 3. Handouts (if applicable)      | 1         | 2    | 3    | 4    |
| 4. Overall evaluation of session | 1         | 2    | 3    | 4    |

5. The best thing about this session was:

---

---

---

---

---

6. This session could have been improved by:

---

---

---

---

---

7. Did you learn of methods for utilizing self-help/mutual support that are needed or missing in your program?

\_\_\_\_\_ yes

\_\_\_\_\_ no

If yes, list specific examples:

---

---

---

---

---

---

8. Based on this session, are there applications of parent empowerment that you intend to use in your professional practice?

\_\_\_\_\_ yes

\_\_\_\_\_ no

If yes, please list specific practices:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If no, list specific obstacles to implementation:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

9. Please use this space for other comments you would like to make about this training session on empowering parents.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

#### Survey of Session Participants' Ethnocultural Background

The Maternal and Child Health Bureau, USDHHS, has requested that we collect the following data. This information is for statistical purposes only and is purely voluntary. Check as appropriate.

|                      |             |                                           |
|----------------------|-------------|-------------------------------------------|
| _____ White          | _____ Black | _____ Black Hispanic                      |
| _____ White Hispanic | _____ Asian | _____ Native American/<br>American Indian |
| _____ Other          |             |                                           |

Please check one: I am a staff member with:

\_\_\_\_\_ PHCP                      \_\_\_\_\_ Early Intervention  
\_\_\_\_\_ Other (Please identify) \_\_\_\_\_

Thank you for taking the time to evaluate this session.

MH038

## Appendix F

# Self-Help Line

Barbara E. Fisher, Director

607-735-4888

NOTE

## SELF-HELP WORKSHOP



*"Tell me more..."*

Facilitating small group discussions

*"Helping people help themselves"*

4817

BEST COPY AVAILABLE

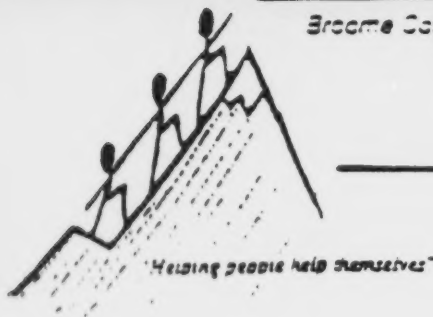
Sponsored jointly by:



MENTAL HEALTH ASSOCIATION

FIRST CALL FOR HELP





Broome County Area Clearinghouse

# Self-Help Line

Barbara E. Fisher, Director  
507-77-4882

MENTAL HEALTH ASSOCIATION  
in Broome County  
32 Oak Street, Binghamton, NY 13901

*"Tell me more..."*

Facilitating  
small group discussions

## WORKSHOP AGENDA

- Introductions: Joyce Stafford, Director of Community Programs, United Way of Broome County  
Billy Jo Wells, Program Coordinator, First Call For Help  
Marion Genser, Education Director, Mental Health Association in Broome County  
Barbara Fisher, Coordinator of Self-Help Line  
Self-Help Line
- Presentation: What is a group? What is a facilitator?
  - Purpose - Mission statement
  - Shared leadership - Responsibilities to each other
  - Active listening
  - Processing what's been shared
  - Handling the difficult - (issues, persons, situations)
  - Ground rules
  - Questions?
- Break
- Group experience:
  - Introductions
  - Select reporter
  - Read ground rules
  - Video
  - Discussion
- Questions?
- Wrap-up
- Evaluation

218



# Self-Help Line

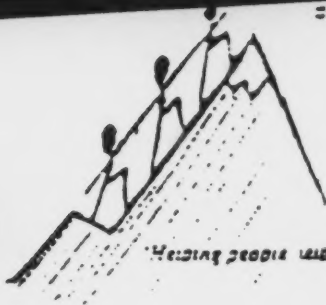
Orange County Area Hearing House

1000 1st Street

MENTAL HEALTH ASSOCIATION

Orange County

32 Oak Street, Binghamton, NY



Helping people help themselves

## ACTIVE LISTENING SKILLS

### Being Attentive - Hang on to every word.

Attentive means listening ever so actively. Look at the person who is talking. Be careful not to drum your fingers, play with pencil, doodle, yawn, glance at your watch, or look away from group. Distracted behavior sends the message, "I'm not paying attention."

### Restating - Repeat what a person says using the same or slightly different wording.

This is the simplest way to let someone know that you're hearing what he/she saying. And, it allows the speaker a chance to correct anything to be better understood.

### Questioning - Get more information and clarifying details.

Avoid asking the judgmental question, "Why?" Rather than asking a direct question that can often be answered with a one-word "yes" or "no," ask the speaker to "tell me more about..." Avoid "cross-examining" or "leading the witness." Don't ask too many questions. Wait for the answer and its details before asking another question.

### Summarizing - Step back and review the "big picture" of what the conversation is about so far.

Useful in helping gain perspective and to see where a person might focus.

### Reflecting Feelings - Identify what you think are the feelings underlying what someone is saying.

Best done in a tentative way, i.e. "It sounds like you were scared at that moment..."

### Validating Feelings - Help a person to feel "OK" about a feeling.

Indicating that you understand how he/she could feel that way. You can validate how someone feels without necessarily approving of how he/she is acting.

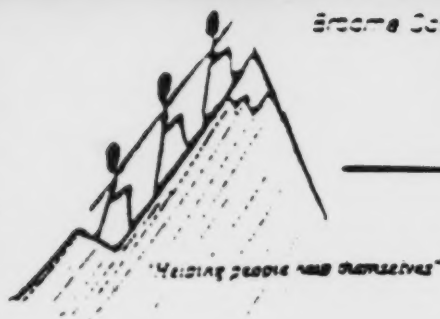
### Holistic Listening - Listen with the "third ear."

Read between the lines of what a person is saying in such a way that you learn something new about the person. Observe the body language. Listen for voice tremors, gestures, rate of breath, sighs, facial color, muscle tension (tight fists), posture, choice of clothing. Are the non-verbals consistent with the verbal communication? If not, you might gently explore your observation with the person talking, i.e. "I noticed you clenched your fist when you mentioned..."

### Listening Across Time - Keep in mind previous discussions.

Patterns of communication, positive changes, recurring themes, or apparent contradictions may develop over the course of several meetings. Affirm the progress you see. Note the inconsistencies.





Broome County Area Clearinghouse

# Self-Help Line

Barbara E. Fisher, Director

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MENTAL HEALTH ASSOCIATION

in Broome County

32 Oak Street, Binghamton, NY 13902

## RESPONSIBILITY OF GROUP MEMBERS TO EACH OTHER

One of the primary purposes of a self-help group is to provide an environment where people with common problems or similar stressful life situations can meet and help each other cope in a supportive, caring, and non-judgmental atmosphere.

In a self-help group, the role of facilitating or leading a group discussion is not the responsibility of one person but is shared by the entire group. Thus, all members need to be aware of their responsibility to:

- Help members feel comfortable and get to know each other.
- Be sure the speaker has finished describing his/her problem before offering suggestions.
- Listen attentively when another member is speaking.
- Discourage side conversations.
- Promote positive comments and new viewpoints. Keep the discussion upbeat, lest the discussion deteriorate into a gripe session.
- Notice silent people in the group and encourage them to contribute.
- Participate in the discussion---share the other's problem; offer ideas and suggestions.
- Recognize when a member's problem is beyond the group's ability to help and be willing to suggest alternative resources outside the group.
- Allow a member to ventilate negative or angry feelings---often this must be done before positive direction can be given or received.
- Assure members that whatever is said in the group, stays in the group (maintain confidentiality.) This is more important in some groups than in others, depending on the sensitivity of the issue or the depth of the sharing.
- Make a commitment to the group, contributing whatever talents, skills, resources, or information needed to assure the group's success and survival.

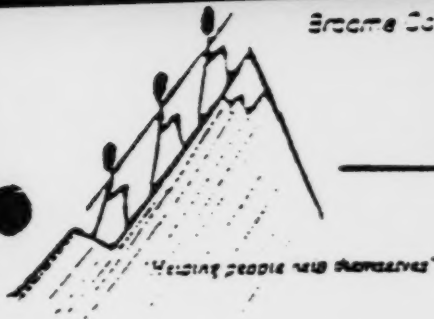
Prepared by New Jersey Self-Help Clearinghouse



# Self-Help Line

Barbara E. Fisher, Coordinator

607 734-8888



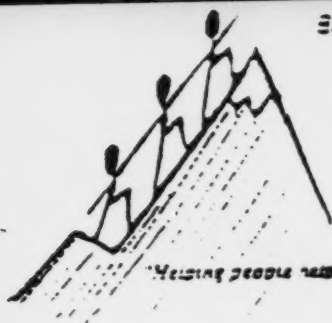
MENTAL HEALTH ASSOCIATION  
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52 Oak Street, Binghamton, NY 13901

## GUIDELINES FOR PARTICIPANTS IN SMALL GROUPS

1. Adults learn best by hearing about the experiences of others, not by getting advice from others. Therefore, say what **YOU** did in a similar situation, rather than say what someone else **SHOULD** do.
2. Inquire to learn more about something. Don't put anyone on trial and don't try to point out the faults in someone else's thinking or actions.
3. Respect the opinions and experiences of others. What doesn't work for you may work for someone else.
4. Share even if you were unhappy about the outcome of some action. It might help someone else avoid repeating your mistake.
5. Stick to the topic.
6. Share the time available in the group. Don't monopolize.
7. Don't expect others to solve your problems or to give you advice.
8. Be open to help from people other than the group facilitator.
9. Be brief.

Prepared by SOS Shelter, Endicott, New York





Broome County Area Clearinghouse

# Self-Help Line

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32 Oak Street, Binghamton, NY 13901

## GUIDELINES FOR FACILITATORS OF SMALL GROUPS

1. Briefly introduce yourself and your qualifications for conducting the group.
2. Briefly introduce the theme/topic of the group and state why you think it will be helpful to the members.
3. Indicate your intentions to stick to the topic. There should be someone available to handle emergencies.
4. Invite all participants to briefly introduce themselves, stating what they hope to get out of the group. Everyone should be introduced before the groups starts.
5. Suggest following the "Participants' Guidelines" as a means of insuring maximum benefit. Read or give them a copy.
6. Don't rely on others in the group to handle "problem" participants (i.e. monopolizers, help-rejecting complainers, prosecutors.) Handle them warmly but firmly. Even intense grief can be contained and it is often helpful to do so.
7. Keep an eye on the time. Help wrap things up at the end. Try not to end early or go overtime. The optimal time is usually about an hour and fifteen minutes.
8. Refer participants to other sources of help if appropriate.

Prepared by SOS Shelter, Enfield, New York

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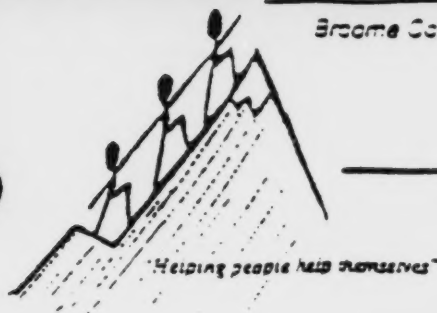
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in Broome County

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Broome County Area Clearinghouse

# Self-Help Line

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## GROUND RULES FOR GROUP DISCUSSION

Self-help groups can be as formal or as informal as their members wish. But, some groups find discussion easier if there are some general guidelines. Here are examples from two self-help groups. Guidelines can be included in the group's brochure or printed as a hand-out to be distributed before discussion (so members know from the outset what the ground rules are.)

From Helping Others - Helping Ourselves, Manic Depressive Disorders Group, Morris County, New Jersey

1. We are a group of people gathered together. We share a common bond. We are here to help ourselves and others by sharing our concerns, our feelings, our strengths, and our wisdom.
2. We maintain trust by respecting the confidentiality of our group, and we have the right to remain anonymous if we so choose.
3. We avoid dominating conversations, and we provide an opportunity for everyone to participate.
4. The responsibilities to myself and to this group include giving thoughtful positive comments, asking questions, and getting statements clarified in order to understand and to be understood.
5. Smoking is allowed upon consent of the group. Each smoker must contain his/her ashes and dispose of them at the end of the meeting.
6. We express our beliefs openly and honestly. We allow others to hold their own beliefs and to express them as well. We observe the right to disagree.
7. We encourage the "I" statement to share how "I" feel.
8. We are each responsible for the success of this group. I will raise my concerns to meet my needs and allow others to do the same.
9. I will listen actively when someone is talking and not have side conversations.
10. Let's deal with "the here and now" for ourselves and others.
11. Any additions to these guidelines should be shared with the group now.

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From FAIR---Family and Individual Reliance Program of Texas Mental Health Association (facing or dealing with mental illness):

- We are a group of people with a common bond, sharing our troubles, understanding, and wisdom.
  - We listen, explore options, and express our feelings. We do not prescribe, diagnose, judge, or give advice---we suggest.
  - We know what we share is confidential and we have the right to remain anonymous if we choose.
  - We have the right to take part in any discussion or not. It is important that we actively listen when someone is talking and avoid having side conversations.
  - We encourage "I" statements, so that everyone speaks in the first person.
  - We invite speakers occasionally for information we want as a group.
  - Having benefited from the help of others, we recognize the need for offering our help to others.
- 

From WE CARE Program of Wilder Foundation in St. Paul, Minnesota (divorced and separated):

- We are here to share our own feelings and experiences. Respect and maintain confidentiality of the group.
- Our goal is to accept people and to avoid making judgments.
- Avoid interrupting. If we do break in, return the conversation to the person who was speaking.
- Side conversations are not allowed.
- We each share the responsibility for making the group work.
- We each have the opportunity for equal air-time or the right to remain silent.
- We try not to discuss persons who are not present.
- We try not to give or take advice.
- We have the right to ask questions and the right to refuse to answer.

To these lists, we suggest one more possible guideline to help keep the discussion and sharing "upbeat." It would be:

- We encourage members to share their strengths, skills, insights, successes (however small), and their hopes.



From REACH group in Winston-Salem, North Carolina

- We are a group of people with a common bond---sharing our troubles, understanding, strength, and wisdom.
- We listen, explore options, and express our feelings. We do not prescribe, diagnose, judge, or give advice---we suggest.
- We know what we share is confidential---we have the right to remain anonymous if we choose.
- We have the right to take part or to remain silent in any discussion.
- It is important that we actively listen when someone is talking---we avoid having side conversations.
- We encourage "I" statements---so that everyone speaks in the first person.
- Having benefitted from the help of others, we recognize the need for offering our help to others in support groups.
- We have the opportunity to participate in advocacy with our sponsoring agency.
- We ask that you do not smoke inside the meeting room. If you must smoke, please sit by the door or step outside.

Prepared by Mental Health Association in Forsyth County  
Winston-Salem, North Carolina

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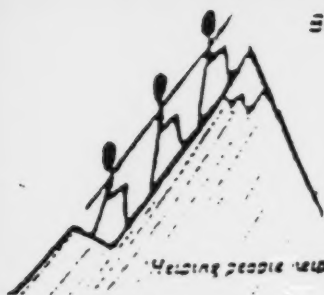
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# Self-Help Line

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in Broome County

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## HINTS FOR FACILITATING A GROUP

### At the beginning of the meeting:

- Provide a relaxed welcoming atmosphere. A cup of coffee or a glass of cider says to members, "I was expecting you. I'm glad you're here." Keep the refreshments simple. Group members may want to contribute by bringing the goodies, but they may feel reluctant if elaborate treats become the norm.
- Read the proposed ground rules aloud. Stating the group's guidelines at the beginning helps newcomers feel comfortable and part of the group, knowing what the group expects. It helps the facilitator keep the discussion appropriate. Without ground rules, the group can become a gossip session, an intellectual discussion, or utter chaos as everyone tries to get into the act simultaneously.
- Get to know each other. Learn each other's first names. Share a little about yourself. The facilitator may wish to tell something about her/himself as a sort of pace setter. When you reveal things about yourself and the struggles you've faced, often others' hesitancy begins to disappear.

### During the group discussion:

- Emphasize confidentiality. Remind participants that when they leave, they leave whatever was shared in the group. Shared information is not to be taken out to others.
- Focus on the persons present---their feelings, frustrations, shared solutions, and perhaps most of all, what they might do for themselves to feel good about themselves.
- Don't allow anyone to talk about someone not present, except in such cases where a regular member is in crisis and in need of the group's support. The details of the crisis don't need to be given unless that member has asked that you share that information.
- Don't allow anyone to impose their solutions, religion, or theories on anyone else. They may state their own beliefs, ideas, and solutions; but they must claim them as their own. Don't allow "You should..." or "You ought..." Shoulds and oughts will wreck a group discussion quickly. The only "should" allowed is that everyone should be allowed to make his/her own decisions.
- When the discussion becomes theoretical or hypothetical, lead with some open-ended questions. Bring the group back to focus on "What going on with you?" "What can we, as a group, do to help you?" "What are some things you do to deal with...?" "Tell me more about..." "Would you like to share more about..."
- Don't allow faulty information to go unchallenged. The group will be looking for information and answers---they have a right to have good, correct resources. If someone presents erroneous info, approach it with "I'd like to know more about this. Where did you get your information? Can you bring us a copy of that?"
- Don't allow anyone to monopolize the discussion. Direct a related question to the rest of the group, such as, "Has anyone else experienced a similar situation or feeling?"



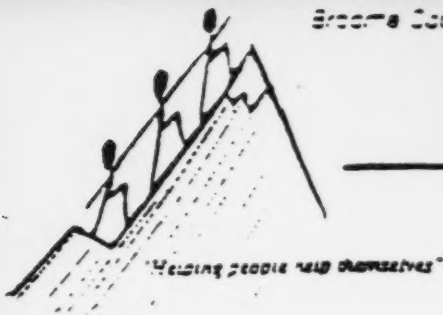
Before the group dismisses:

- Recap what has been covered. Give everyone a minute or two to say how they are feeling right now.
- Try to close with a pleasant thought, poem, or light story. Encourage everyone to stay and socialize.
- Remind everyone of the day, date, and time of next meeting.

Adapted from Help is within REACH

Mental Health Association in Forsyth County, Winston-Salem, North Carolina.





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## WAYS TO RESPOND TO DISRUPTIVE BEHAVIOR

### MONOPOLIZING:

1. When the monopolizer pauses or stops for breath, ask for comments from others.
2. Gently but firmly interrupt, validating the speaker's contribution yet indicating the need to move on.
3. Take care not to reinforce the individual's tendency to dominate. Setting limits on excessive talking can be reassuring to the monopolizer and to the rest of the group.
4. Establish ground rules that encourage everyone to participate.
5. Support other participants when they contribute to bolster their confidence and reinforce their efforts.
6. Encourage other members to break in to the discussion and deal with the monopolizer themselves.
7. Don't ally yourself with the monopolizer.
8. Speak to the person privately about his/her tendency to dominate the discussion. Describe the difficulties this creates.
9. When all else fails and the group shows signs of faltering, ask the person to withdraw.

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### WITHHOLDING/SILENCE:

1. Plan an exercise that allows participants to work in pairs. This usually produces less anxiety than talking to the whole group.
2. Develop a repertoire of small group exercises.
3. Encourage people who are giving nonverbal clues that they have something to say.
4. Let people know that differences of opinion are not only tolerated, they are welcome.
5. Make sure the agenda interests silent members and that their concerns/questions are being addressed.
6. Make an extra effort to establish a rapport with these silent individuals. A few minutes of conversation before or after a session, eye contact, smiles, etc. ---all these invite a response.
7. Encourage contact between the quiet person and other group members by suggesting car pools, sharing books/articles, organizing refreshments.
8. Offer opportunities to participate in non-verbal ways.
9. Speak privately with people who persist in remaining silent.

### ANTI-PARTICIPATORY OR NEGATIVE ATTENTION SEEKING:

1. Keep the focus on the issues rather than on the person.
2. Avoid taking sides, especially in a group that represents a range of values.
3. When responding to a value judgment, present both the advantages and disadvantages of that value.
4. Accurate information or knowledge, if known, should be shared even if it means tactfully correcting distorted or erroneous facts offered in the group.
5. Involve the group in making decisions or solving problems posed by the difficult person.
6. Seek feedback often, setting aside time to explore ways in which the group is or is not meeting participants' needs.
7. Mention your concern that the atmosphere and/or dynamics in the group may be hindering group solidarity. Do not label or blame any one person. Attribute the problem to a lack of communication or misunderstanding.
8. Speak privately to the negative attention seeker. Offer alternative or additional services to meet the person's needs.
9. Assign specific tasks to the negative group member to redirect his/her energy into helpful channels.

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## SELECTED HIGHLIGHTS OF RESEARCH ON EFFECTIVENESS OF SELF-HELP GROUPS

Compiled by Louis J. Medvene, Ph.D.

Research on the effectiveness of participation in self-help groups which is methodologically rigorous is just beginning. The following highlights are taken from a variety of different studies including research which involved comparisons of self-help groups with "no treatment" or "control groups", as well as studies which simply involved self-reported benefits. Only studies reporting positive results are included.

### COPIING WITH ACUTE AND CHRONIC HEALTH PROBLEMS:

- High risk male and female patients with chronic airway obstructions (emphysema, chronic bronchitis, or asthma) who participated in a self-help group were less likely to be hospitalized (20% vs 64%) and to be hospitalized for shorter periods of time (0.8 days vs 5 days) than other high-risk patients who were in a wait list control condition. The study followed 31 high-risk patients, whose median age was 64, for a six-month period. Ten high-risk patients were randomly assigned to each of three conditions: a lay-led self-help support club, a professionally-led educational rehabilitation group, and a wait list control condition. (Jensen, 1983)
- Male and female smokers who participated in support groups, and used smoking cessation manuals and watching relevant television programming, had higher quit rates after a three-week intervention than comparable others who only used manuals and watched television (41 percent vs 21 percent). At three month follow-up employees in the group condition maintained higher cessation rates (22 percent vs 12 percent). Participants were 525 employees from 43 corporations who were assigned at random to the support group condition (n=233) or the non-group condition (n=192). (Jason, Gruder, Martino, Flay, Warnecke & Thomas, 1987)
- Male and female adults who had undergone surgery or bracing for treatment of scoliosis and who participated in Scoliosis Peer Support groups had, in comparison with non-participating similar others: fewer psychosomatic symptoms, higher feelings of mastery, fewer feelings of shame and estrangement, higher self-esteem, a more positive outlook, and better patient-physician relationships. Survey questionnaires were gathered from 245 scoliosis club participants and 495 nonparticipants who were interested in joining. Adults who had undergone medical treatment benefited most: minimal gains were reported by other adults and adolescents with scoliosis, as well as parents of adolescents with scoliosis. (Hinrichsen, G., Revenson, T. & Shinn, 1985)
- Women with metastasized breast cancer who participated in a weekly support group had significantly lower mood disturbances, fewer maladaptive coping responses, and

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were less phobic than a group of similar others who did not participate in a support group. Women were randomly assigned to either a support group or a no treatment control condition. After one year, the 34 women in the support group condition were compared with the 24 women in the control condition. (Spiegel, D., Bloom, J.R., & Yalom, L. 1981)

- \* Men and women with rheumatoid arthritis who participated in a mutual support group showed greater improvement in joint tenderness than did a similar group of non-participants. A total of 105 patients were randomly assigned to one of three conditions: stress management group, mutual support group, or a no treatment group. The stress management and support groups met for ten weekly sessions and were facilitated by a psychologist. (Shearn, M.A. & Fireman, B.H., 1985)
- \* Male and female members of the United Ostomy Association (UOA) who participated as visitors in UOA's program were significantly more accepting of their ostomies than other members who were not visitors. Acceptance of ostomy is associated with better acceptance of the drastic life changes resulting from ostomy surgery, with better health, and with the ability to maintain social relationships. Three-hundred-and-eighteen people responded from 25 UOA chapters (54% were visitors and 46% were non-visitors. (Trainor, M.A., 1982)
- \* Women who had undergone mastectomy operations and who participated in Reach-To-Recovery's visitor program found the visits very helpful. Participants who were visited by a Reach-To Recovery member returned to normal activities earlier than similar others. The findings were based on personal interviews with 652 women. (Rogers, T.F., Bauman, L.J. & Metzger, L., 1985)
- \* People participating in a self-help group for laryngectomized cancer patients improved their communication abilities, functioned well socially, and tended not to experience serious post-surgical depression. Findings based on interviews with 60 patients. (Richardson, 1980)
- \* Male and female cancer patients who were undergoing or had completed lengthy cancer therapy and who joined TOUCH, a self-help group which includes training to help similar others, reported that they benefited significantly in terms of their knowledge of cancer, their ability to talk with people, their friendships and family life, and their coping with cancer. One-hundred-and-thirty-nine people (70% response rate) who were active in seven different groups responded. (Maisiak, R., Cain, M., Yarbrow, C.H. & Josof, L., 1981)
- \* Men and women with multiple sclerosis (MS) who participated in a support group led by a registered nurse with MS felt they benefited by gaining information about MS, about how to care for themselves, and about how to recognize and deal with common aspects of their illness like forgetfulness and euphoria. (Spiegelberg, N., 1980)

#### COPING WITH STRESSFUL EVENTS OR LIFE TRANSITIONS:

- \* Parents of premature infants who participated in a support group animated by a "veteran" mother behaved significantly differently towards their infants than did a non-participating comparison group of similar others. In comparison with the control group.

families which participated visited their infants significantly more often in the hospital, touched, talked, and looked at their infants significantly more often, and rated themselves as more competent infant care givers. The 28 families in the support group condition met for seven to ten weeks and were compared to 29 control families. All families were followed for three months. (Minde, K., Shosenberg, N., Marton, P., Thompson, J. & Ripley, J., 1980)

- Parents who participated in a self-help group reported that they felt more positive and less alone in their new role as parents. Skill in caring for their child increased, and understanding of their child's normal growth and development improved. Ninety-eight parents responded to mailed survey questionnaires two years after the support group program had been initiated. (Kagey, J.R., Vivace, J. & Lutz, W., 1981)
- Widows paired with a widow contact who provided emotional support and practical assistance coped with their loss significantly better than did a group of unpaired similar widows. At six months, the "supported" widows who were most distressed initially were more likely to feel "better" and were less likely to anticipate difficulties adjusting to widowhood. At 12 months, these widows were significantly more likely to have made new friends and to have begun new activities. And at 24 months, these widows were significantly less distressed than similar unpaired widows. On the basis of random assignment, 68 women were placed in the intervention condition and 94 in a no treatment control condition. Most of the gains were comparison with highly distressed women in the control condition. (Vachov, M.L., Lyall, W.A., Rogers, J., Freedman-Letofsky, K. & Freeman, S.J., 1980)
- Members of THEOS (They Help Each Other Spiritually), a self-help organization for recently widowed persons, showed improvement in sense of well-being, self-esteem and sense of mastery over a one year time period, while a normative sample of bereaved persons, not in THEOS, showed deterioration in these areas. Members who developed social linkages within the group showed more positive changes than other participants: less anxiety and use of psychotropic medication and increased sense of well-being and mastery. The study involved two survey questionnaires mailed one year apart to members (n=376) and a probability sample of similarly bereaved persons. (Lieberman & Videk-Sherman, 1986)
- Bereaved parents who participated in Compassionate Friends (CP), a group for parents who have lost children, felt they had been helped by their involvement. In comparison to relatively inactive members and parents who declined invitations to join CP, the most active participants experienced significantly more personal growth, especially in the areas of greater sense of personal strength and resiliency. They also felt they gained an increased sense of the value of human life. The findings were based on the analysis of two survey questionnaires mailed at a one-year time interval. One hundred ninety-four parents responded. (Videka-Sherman, L., 1982)
- Nurses on a pediatric Intensive Care Unit (ICU) who participated in a support group reported that participation improved their morale and communication skills. Additionally, the turnover rate of the participating nurses was reduced, while the rate increased in their hospital. (Weiner, M.F., Caldwell, T., 1983-1984)

## MENTAL HEALTH

- Patients discharged from a state psychiatric hospital who were randomly assigned to participate in a Community Network Development (CND) Program (n=40) required one-half as much re-hospitalization ten months after discharge, as a comparable group of non-participating ex-patients (n=40). CND ex-patients also required one-third as many patient days of re-hospitalization (7 vs 25 days), and a significantly smaller percentage of them needed to continue to participation in a CND network involved monthly social activities and weekly contact by a paid CND member. (Gordon, R.E., Edmunson, E. & Bedell, J., 1982)
- Men and women who participated in Recovery, Inc., a self-help program for people with a history of psychiatric problems, reported less nervousness, tension and depression since joining the group. Long-term members who were leaders reported a diminished need for professional psychotherapy and medication and were indistinguishable from a probability sample of community members on self-reported measures of general well-being. Respondents were 201 Recovery, Inc., group leaders who had been members for at least 7 years, 155 short-term members, and 195 control subjects who represented a probability sample from the community. (Galanter, 1988)
- Children of parents with drinking problems who participated in Alateen, a self-help group sponsored by Alcoholics Anonymous, suffered less emotional and social disturbance than peers who did not belong. The findings were based on personal interviews with three groups of matched participants: adolescents with an alcoholic parent who were not members of Alateen, adolescents who were members of Alateen, and a control group of adolescents without an alcoholic parent. There were 25 adolescents in each group. (Hughes, J.M., 1977)
- Participation in a self-help group for families of psychiatric patients reduced the family's sense of burden. Members found the group helpful because it provided them with information about schizophrenia and coping strategies which professionals didn't provide. Participation also helped parents to develop supportive social bonds with others who were experiencing similar problems. Fifty-six families responded to a mailed questionnaire. (Potasznik, H. & Nelson, B., 1984)
- Child abusers who participated in Parents Anonymous, a self-help group for abusive parents, reported that they gained insight into their reactions to the abuse they typically experienced as children and that they learned new ways of expressing love and affection to their own children. (Comstock, C., 1982)
- Participants in a national self-help group for parents of young drug and alcohol abusers -- PRIDE (Parent Resources Institute for Drug Education) -- reported that their participation was associated with improvement in their children's drug problem. A majority of the participants also reported improvements in their children's general discipline problems and in adjustment outside the home. Findings were based on the



analysis of the responses of 135 parent group members to a written questionnaire. (Galanter, M.D., Gleaton, T., Marcus, C.E. & McMillen, J., 1984)

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- Health Resources, Vol. 2, No. 9, Sept. 1987.

"An invaluable resource for the individual, the family, and the professional, or anybody who is looking for support from a group ... [Its price] is about the equivalent of 25 fruitless phone calls and 40 miles of wasted driving".

- The Woman's Newspaper, (a tri-state award-winning publication), May '87, Princeton.

"With this book you're literally never more than a commercial break away from practically any resource you can think of - nationwide...however, it is only 130 pages and takes great pains to give you the national number that can then refer you to the nearest local group that can help one find peers who can relate to just about every issue that you could possibly imagine ... and then some. As if that were not enough, they have an excellent section on guidelines for starting self-help groups..."

- Michael S. Broder, Ph.D. in the AMPLifier, Association for Media Psychology, Spring '87.

"With a growing recognition of the value of self-help, nurses are often approached for information about existing self-help groups or maybe even how to start one. Perhaps the most comprehensive resource available to serve both of these needs is a new publication... The wealth of information compiled in this compact directory, coupled with its easy to use format, make it a valuable resource..."

- Judy A. Rollins, BA, RN in Pediatric Nursing, July-August 1987, Vol. 13, No. 4.

"Written for the lay public, this book would be useful for those who work (directly or indirectly) with people in situational crisis. It provides possible resources for referral by therapists, health care providers, teachers, and other concerned professionals in addition to guidelines for starting self-help groups." - Linda Ade-Ridder in Family Relations: Journal of Applied Family & Child Studies, Apr '87.

"This book can certainly help anyone trying to find assistance by simply being an invaluable source of information..." - Medical Update Newsletter, 10 (9), Mar '87.

"This compact book holds an immense amount of information for those in search of a self-help group..." - Jack Mayes in Networking Newsletter, Vol. 3, No. 2, 1987.

## Empowering Families Through Self-Help/Mutual Support

### BIBLIOGRAPHY

Nathanson, Minna. Organizing and Maintaining Support Groups for Parents of Children with Chronic Illness and Handicapping Conditions, Association for the Care of Children's Health, Bethesda, MD, 1986.

A practical handbook that describes the "how-to's" of establishing and running a parent support group. In loose-leaf format. 102 pages.

Available from: Association for the Care of Children's Health  
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Bethesda, MD 20814-3015  
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## Your 1992-1993 guide to helpful information, resources and referral services

You can get referrals and information about a wide variety of problems by picking up your telephone. Many of the numbers listed here are toll-free, but we've included a few that are not because they offer much needed information or support about difficult issues. There may also be organizations in your community that can help. Most numbers do not answer 24 hours a day, so keep trying to get through.

### AGING

|                                            |               |
|--------------------------------------------|---------------|
| Alzheimer's Association .....              | (800)272-3900 |
| In IL .....                                | (800)572-6037 |
| Mature Outlook .....                       | (800)336-6330 |
| National Eye Care Helpline (over 65) ..... | (800)222-EYES |

### AIDS

|                                         |               |
|-----------------------------------------|---------------|
| AIDS Hotline .....                      | (800)342-AIDS |
| In Spanish .....                        | (800)344-SIDA |
| TTY/TDD (deaf) .....                    | (800)243-7889 |
| National AIDS Information               |               |
| Clearinghouse .....                     | (800)458-5231 |
| NIDA AIDS Helpline (drug abusers) ..... | (800)662-HELP |
| Project Inform Hotline .....            | (800)822-7422 |
| In CA .....                             | (800)334-7422 |
| In San Francisco .....                  | (415)858-9051 |

### BIRTH DEFECTS

|                                           |               |
|-------------------------------------------|---------------|
| American Association on Mental            |               |
| Retardation .....                         | (800)424-3688 |
| In DC .....                               | (202)387-1968 |
| American Cleft Palate Foundation .....    | (800)24-CLEFT |
| Cystic Fibrosis Foundation .....          | (800)344-4823 |
| In MD .....                               | (301)951-4422 |
| National Down Syndrome Congress .....     | (800)221-NDSC |
| National Easter Seal Society .....        | (800)221-6827 |
| Spina Bifida Association of America ..... | (800)621-3141 |
| In D.C. ....                              | (202)944-3285 |

### CANCER

|                                       |               |
|---------------------------------------|---------------|
| American Cancer Society .....         | (800)227-2345 |
| Cancer Information Hotline .....      | (800)525-3777 |
| Cancer Information Service .....      | (800)4-CANCER |
| National Brain Tumor Foundation ..... | (415)296-0404 |

|                                                          |               |
|----------------------------------------------------------|---------------|
| Y-ME National Organization for Breast Cancer Information |               |
| and support .....                                        | (800)221-2141 |
| (24 hour) .....                                          | (708)999-8223 |

### CHILD HEALTH

|                                                           |               |
|-----------------------------------------------------------|---------------|
| American Sudden Infant Death                              |               |
| Syndrome Institute .....                                  | (800)232-SIDS |
| In GA .....                                               | (800)847-7437 |
| Children's Hospice Intl. ....                             | (800)24-CHILD |
| In VA .....                                               | (703)684-0330 |
| Children's Wish Foundation Intl. ....                     | (800)323-9474 |
| SIDS Alliance .....                                       | (800)638-SIDS |
| or .....                                                  | (800)221-SIDS |
| National Information Center for Children                  |               |
| with Handicaps .....                                      | (800)999-5599 |
| National Information System for Health Related Services - |               |
| (disabled/chronically ill under 21) .....                 | (800)922-9234 |
| In SC .....                                               | (800)922-1107 |
| National Rey's Syndrome Foundation .....                  | (800)233-7393 |
| In OH .....                                               | (800)231-7393 |
| Order of United Commercial Travelers of America           |               |
| (retarded children) .....                                 | (800)848-0123 |
| Shriners Hospital Referral Line .....                     | (800)237-5055 |

### CRIME

|                                           |               |
|-------------------------------------------|---------------|
| National Criminal Justice Referral System |               |
| (victims) .....                           | (800)851-3420 |
| National Victims' Resource Center .....   | (800)627-6872 |

### CONSUMER

|                                             |               |
|---------------------------------------------|---------------|
| Conservation & Renewal Energy Hotline ..... | (800)523-2929 |
| Consumer Product Safety Commission .....    | (800)638-CPSC |
| MACAP (Major Appliance Consumer             |               |
| Action Panel) .....                         | (800)621-0477 |
| National Insurance Consumer Helpline .....  | (800)942-4242 |



## DERMATOLOGY

- Acne Helpline ..... (800)221-SKIN  
 or ..... (800)222-SKIN  
 Facial Plastic Surgery Information  
 Service ..... (800)332-FACE  
 Cosmetic Surgery Information Service ..... (800)221-9808  
 American Society of Plastic and Reconstructive Surgeons  
 Referral Service ..... (800)635-0635

## DISABILITY

- HEATH Resource Center (postsecondary education for  
 the handicapped) ..... (800)544-3284  
 In DC ..... (202)939-9320  
 Job Accommodation Network ..... (800)526-7234  
 In WV ..... (800)526-4698

## DISEASES AND CONDITIONS

- ADA Diabetes Information Service ..... (800)232-3472  
 ALS Association ..... (800)782-4747  
 American Dental Association ..... (800)621-8099  
 American Kidney Fund ..... (800)638-8299  
 American Leprosy Missions ..... (800)543-3131  
 American Liver Foundation ..... (800)223-0179  
 In NJ ..... (201)857-2626  
 Arthritis Medical Center ..... (800)327-3027  
 In Ft. Lauderdale, FL ..... (305)739-3202  
 Autism Society of America ..... (301)565-0433  
 Cooley's Anemia Foundation ..... (800)221-3571  
 Epilepsy Foundation ..... (800)EFA-1000  
 In MD ..... (301)489-1000  
 Baltimore affiliate ..... (800)492-2523  
 Huntington's Disease ..... (800)345-4372  
 Immunodeficiency Foundation ..... (410)461-3120  
 Juvenile Diabetes Foundation (info) ..... (800)223-1138  
 Lupus Research Institute ..... (800)82-LUPUS  
 Lupus Foundation ..... (800)558-0121  
 Lymphoderma Network ..... (800)541-3259  
 National Association for Sickle  
 Cell Disease ..... (800)421-8453  
 National Foundation for Ileitis  
 and Colitis ..... (800)343-3637  
 National Headache Foundation ..... (800)843-2356  
 National Heart, Lung, and Blood Institute ..... (301)496-1051  
 National Health Center ..... (800)336-4797  
 National Organization for Rare Disorders ..... (800)999-6673  
 United Scleroderma Foundation ..... (800)722-HOPE

## EATING DISORDERS

- Rader Institute ..... (800)255-1818

## ENVIRONMENT

- Conservation and Renewal Energy Hotline ..... (800)523-2929  
 Environmental Protection Agency Hotline ..... (800)424-4000  
 Pesticide Telecommunications Network ..... (800)858-7373

## FAMILY

- Child Help USA National Iowa Forester's Child Abuse  
 Hotline ..... (800)4ACHILD  
 Child Care Information Service ..... (800)424-2460  
 Child Find of America ..... (800)1-AM-LOST  
 CHOICES (child/elder care) ..... (800)827-5335  
 Domestic Violence Hotline ..... (800)333-SAFE  
 Missing Children Help Center ..... (800)USA-KIDS  
 National Center for Missing and  
 Exploited Children ..... (800)843-5678  
 National Committee for Citizens  
 In Education ..... (800)NETWORK  
 National Council on Child Abuse and  
 Family Violence ..... (800)222-2000  
 Parents Anonymous (stressed parents) ..... (800)421-0353

## GOVERNMENT

- Federal Election Commission ..... (800)424-9530  
 In DC ..... (202)376-3120  
 Government Homes and Properties  
 Listing ..... (800)431-6000

## HEALTH REFERRAL

- Adventist Health Network of  
 North America ..... (800)253-7077  
 American Hospital Association ..... (312)280-6000  
 Hill Burton Hospital Free Care ..... (800)638-0742  
 In MD ..... (800)492-0359  
 Hospice Education Institute ..... (800)331-1620  
 In CT ..... (203)767-1620  
 Medic Alert Foundation International ..... (800)ID-ALERT  
 National Association of Rehabilitation  
 Services ..... (800)368-3513  
 Minority Health Resource Center ..... (800)444-6472  
 National Rehabilitation Information  
 Center ..... (800)34-NAR C

Disease Prevention and Health Promotion ..... (800)336-4797  
 In MD ..... (301)565-4167

## HEARING AND SPEECH

American Speech, Language, and Hearing  
 Association ..... (800)633-8255  
 Deafness Research Foundation ..... (800)535-DEAF  
 Dial-A-Hearing Test ..... (800)222-EARS  
 Domestic Violence (for the hearing  
 impaired) ..... (800)873-6363  
 Grapevine (voice and TDD) ..... (800)352-8888  
 In CA ..... (800)2-TRIPOD  
 Hear Now (financial aid) ..... (800)648-HEAR  
 Hearing Aid Helpline ..... (800)521-5247  
 In MI ..... (313)478-2610  
 Hearing & Speech Action National  
 Association ..... (800)EAR-WELL  
 In MD ..... (301)397-8682  
 National Center for Stuttering ..... (800)221-2483  
 In NY ..... (212)532-1460

## INJURY/TRAUMA

American Paralysis Association ..... (800)225-0292  
 In NJ ..... (201)379-2690  
 American Trauma Society ..... (800)556-7890  
 National Spinal Cord Injury Association ..... (800)962-9629  
 In MA ..... (617)935-2722  
 Spinal Cord Injuries Hotline ..... (800)526-3456

## LEARNING DISORDERS

Dyslexia Society ..... (800)222-3123  
 In MD ..... (301)296-0232  
 HEATH Resource Center ..... (800)544-3284  
 In DC ..... (202)939-9320

## LUNGS/ALLERGIES

Allergy Information Center Hotline ..... (800)727-5400  
 Asthma, Allergy Information  
 and Referral ..... (800)822-ASMA  
 Lung Line ..... (800)222-LUNG

## MENTAL HEALTH

American Mental Health Fund ..... (800)433-5959  
 National Foundation for Depressive Illness ..... (800)248-4344

## NEUROLOGICAL

American Parkinson's Disease Association ..... (800)223-2732  
 Cornelia de Lange Syndrome ..... (800)223-8355  
 In CT ..... (203)693-0159  
 Epilepsy Foundation of America ..... (800)EFA-1000  
 National Multiple Sclerosis Society ..... (800)624-6236  
 National Neurofibromatosis Foundation ..... (800)323-7938  
 In NY ..... (212)460-8980  
 National Tuberous Sclerosis Association ..... (800)CAL-NTSA  
 In MD ..... (301)459-9888  
 Parkinson's Disease Foundation ..... (800)457-6676  
 Parkinson's Information Line ..... (800)344-7872  
 Tourette's Syndrome Association ..... (800)237-0717  
 In NY ..... (718)224-2999

## ORGAN TRANSPLANT

Kidney Foundation ..... (800)ACT-GIVE  
 Living Bank (organ donation) ..... (800)528-2971  
 Organ Donor Hotline ..... (800)242-DONOR

## SAFETY

Aviation Safety Institute ..... (800)848-7386  
 In OH ..... (614)885-4242  
 Auto Safety Hotline ..... (800)424-9393  
 Auto Tire Tips ..... (800)382-0600  
 Bikers Against Manslaughter ..... (800)4-BIKERS  
 National Safety Council ..... (800)621-7619  
 Safe Boating ..... (800)336-BOAT  
 In VA ..... (800)245-BOAT  
 U.S. Coast Guard Boating Safety  
 Administration ..... (800)368-5647

## SEXUALITY

Herpes Hotline ..... (919)361-8483  
 National Sexual Addiction Hotline ..... (800)321-2273  
 Recovery of Male Potency ..... (800)835-7667  
 Sexual Addiction Information ..... (800)321-2273

## SUBSTANCE ABUSE

Al-Anon Family Group Headquarters ..... (800)356-9995  
 In NY and Canada ..... (212)245-3151  
 Alcoholics Anonymous World Services ..... (212)870-3400  
 Cocaine Hotline ..... (800)COCAINE  
 Cottage Program ..... (800)752-6100



Drug Abuse Resistance Education ..... (800)223-DARE  
 In Spanish ..... (800)66-AYUDA  
 Just Say No Kids Club ..... (800)253-2766  
 National Council on Alcoholism ..... (800)NCA-CALL  
 National Council on Alcoholism & Drug  
 Dependency ..... (800)475-HOPE  
 National Institute on Drug Abuse ..... (800)662-HELP  
 National Parents' Resource Institute for Drug  
 Education ..... (900)988-PRIDE  
 Substance Abuse Information (South Oaks Psych.  
 Hosp.) ..... (800)732-9808  
 Target Resource Center (education) ..... (800)366-6667

## TEENAGERS

Covenant House (runaways) ..... (800)999-9999  
 National Runaway Switchboard  
 (also suicide counseling) ..... (800)621-4000  
 Runaway Hotline ..... (800)231-6946  
 In TX ..... (800)392-3352  
 United Student Aid Funds ..... (800)428-9250

## VISION/BLINDNESS

American Council for the Blind ..... (800)424-8666  
 American Foundation for the Blind ..... (800)232-5463  
 In NY ..... (212)620-2147  
 Foundation for Glaucoma ..... (415)986-3162  
 Center for Corrective Eye Surgery ..... (800)I-CAN-SEE  
 Library of Congress National Library Services for the Blind  
 and Physically Handicapped ..... (800)424-8567  
 In DC ..... (202)707-5100  
 National Library Service for the Blind and Physically  
 Handicapped ..... (800)424-9100  
 National Federation of the Blind ..... (800)638-7516  
 National Society to Prevent Blindness ..... (800)221-3004  
 Retinitis Pigmentosa Foundation ..... (800)683-2300  
 In MD ..... (301)225-9400

## WOMEN

ASPO/Lamaze ..... (800)368-4404  
 Edna Gladney Center ..... (800)433-2922  
 Endometriosis Association ..... (800)992-ENDO  
 National Black Women's Health  
 Project ..... (404)753-0916  
 National Job Problem  
 Hotline ..... (800)552-0925  
 Women's Sports Foundation ..... (800)227-3983

## MISCELLANEOUS

Aerobics and Fitness Foundation ..... (800) BE-FIT-86  
 American Animal Hospital Association ..... (800)252-AAHA  
 Office of Immigrant and Refugee Affairs (Department of  
 Justice) ..... (800)424-9304  
 Immigration Related Unfair Employment ..... (800)255-7638  
 Compulsive Gambling Hotline ..... (800)332-0402  
 Office of Refugee Resettlement ..... (800)327-3463  
 In FL ..... (800)432-0908  
 World Ministries Commission  
 (disaster relief) ..... (800)323-8039  
 Vietnam Veterans of America ..... (800)424-7275

## LOCAL NUMBERS

## Appendix G



# STATE OF NEW YORK DEPARTMENT OF HEALTH

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Loma McBarnette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

June 28, 1992

Dear Participants, "Empowering Families through  
Self-Help/Mutual Support":

When we met recently at the training session on self-help/mutual support, many of you raised questions about how to involve fathers in mutual support. As promised, enclosed are several articles on the topic and information you may wish to order.

If you have any questions, please do not hesitate to contact me at 518-474-6781.

Sincerely,

Mary Huber

Director

"Partners in Health"

(Enclosure)

cc: Lavonne Bonser  
Sue Messenger  
Cathy Stein  
Elaine MacCormac

a:MH002

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# ChildLink



For SPANS grant recipients and others serving children with special health care needs • Volume 2 • Number 2 • Summer 1993

## S.E.F.A.M. FAMILY SUPPORT PROGRAM—Advocating For Fathers of Special Needs Children

**T**he S.E.F.A.M. (Supporting Extended Family Members) Family Support Program addresses the special needs of fathers. Begun in 1981 at the University of Washington Child Development and Mental Retardation Center, the program has been based at the MerryWood School in Bellevue, Washington, a birth to three early intervention agency, since 1986. Funds provided by the Department of Education (1986-1987) and the Office of Maternal and Child Health (1987-present) have allowed the program to be replicated across the country.

S.E.F.A.M. was developed on the premise that a special needs child impacts the entire family system. When dynamic family changes occur, some members often receive less attention than others, typically grandparents, siblings and fathers. For dads the reasons for this are numerous, not the least of which is that service delivery to the child regularly occurs during a father's working hours; thus dad falls behind in attaining knowledge about the child's special health needs and the interventions available to assist a child's developmental growth. Research details fathers staying in denial longer than mothers in terms of acceptance of a child's problems. Furthermore, few men have role models who have taught them how to nurture a child with special needs. Learning to be appropriate in interacting with the child, knowing how to express emotions of sadness and depression, being able to ask for help are areas many fathers approach with discomfort. Too often men are isolated and neglected. Yet we know a father's role in providing support to his spouse and serving as a model for his children plays a vital part in overall family health (Frey, Fewell, Vadasy & Greenberg, 1989).

A demonstration support group was developed in 1981. The philosophy of the program has

remained consistent over the years: that fathers have the potential to be each other's best resource. The program is designed for fathers, conducted by fathers and assisted by a professional. It is comprised of three major elements: a father-child activity, an open discussion time to allow men to share feelings and concerns about their children and their families, and a speaker to address topics of singular interest to the men. The latter component is also open to mothers who wish to attend. A day care program is available so fathers may bring all of their children if they so desire. There is also a strong social component in most groups. Men attend sporting events together, and participate in activities with their children and families such as swimming, camping, visiting zoos or children's museums. Many groups are also activity based, building adaptive equipment or developing strong advocacy networks to lobby for better financial support for special needs families. Each program decides what it wants to be, based on the needs of the men and the "culture" of the area. There are presently 39 programs in 24 states. The majority of groups have co-facilitators, a dad with a special needs child and a male professional well versed in group dynamics and issues of children with chronic illness or disabling

conditions. The professional assists in facilitating group dynamics, finding appropriate resources (speakers, materials) and providing men with help where needed. The father recruits other men, runs meetings, assesses the interests of the dads, and is the credibility base for the program. Most groups meet on Saturday morning, the time when both fathers and children are best able to attend.

It is up to the group to decide such matters as when they meet, what norms will exist, and what they want to do. Strong bonds between the men and their families exist, and they become powerful support networks for each other. Outcomes include learning to read and interpret a child's communication cues and behaviors; practicing caregiving skills; learning to play appropriately with the child; improved knowledge about chronic illness and disabilities; and sharing personal concerns with other men, and providing respite for mother and other siblings.

The program is family-centered in its intent and outcome. Mothers heartily endorse the program. Beyond the respite, of greater benefit is the increased involvement of the father with the children and accompanying caretaking concerns. Lines of communication are enhanced; decision making becomes increasingly collaborative, and inter-familial tensions are reduced. There is also continual conversation regarding other family members, specifically grandparents and siblings. The numerous social events encompass all of the extended family.

Assessment of families has been an integral part of the program. Using different evaluation tools, researchers have arrived at

(continued on page 8)



*continued from page 7)*

the following conclusions: fathers and mothers experience significantly less stress and sadness; improved self-esteem of both parents is evident; and families are seen as having significantly fewer problems in dealing with the special needs child (Vacasy, Meyer, Fewell and Greenberg, 1985). Other results include improved family communication, increased acceptance of the child, more consistent disciplining of the child, and overall improved harmonious family functioning (Markowitz, 1983). Recent research indicates these benefits appear to endure over time. Parents are better able to "downplay comparison of their special child with normally developing children, focusing rather on comparison with similar children or on improvement over time." This appropriate standard of comparison is judged to be "the single-most important predictor of parental adjustment and satisfaction" (Frey, et al, 1989).

The S.E.F.A.M. program allows fathers to come to terms with their grief as well as find new definitions for parental success. Most men say their ideals and values for parenting have been forever changed due to their special needs children. Support networks for fathers allow changes to happen in an environment of support and education. Their increased competence in nurturing and caretaking will produce positive results for the entire family.

**For More Information Contact:**  
James May  
SEFAM Family Support Program  
MerryWood School  
16120 Northeast Eighth Street  
Bellevue, WA 98008

*Special Kids, Special Dads—  
Fathers of Children with  
Disabilities* (video: 23.25 minutes)  
Contact: SEFAM Family  
Support Program  
James May  
Merrywood School  
16120 N. E. Eighth Street  
Bellevue, WA 98008  
Cost: \$80 plus \$3 shipping/  
handling

245

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# Guidelines for Facilitating Father Support Groups

*from The National Fathers' Network Newsletter, Fall 1991*

**1. Build Your Group From Within** — Assure the members that this is their group, that it will be structured to fit the needs and concerns of the men involved. Periodic needs assessments assist this goal.

**2. Establish Group Norms** — Be clear on the group's purpose, time and length of meetings, and expectations group members have of each other. Norms need to be acceptable to all members and should be periodically reviewed. Consider such areas as confidentiality, sharing of group responsibilities, listening, and respecting ideas (particularly those different from one's own).

**3. Begin Each Session With A "Check In"** — Not a rigid rule, but often useful in many groups. Involves a *brief* statement from each group member indicating who he is, what his child's special needs are, and what is going on in his and his family's life. Some groups find it valuable to end with each participant sharing what the session has meant to him and what he learned or discovered during the session.

**4. Focus On Feelings** — Place primary emphasis on the men's feelings, and avoid intellectualizing and debating of ideas. This a place for support. Do not be afraid to talk about topics such as grief, guilt, anger, depression, and sadness. These are the issues the men have in common and are the concerns that make the group important to those who attend.

**5. Guide The Interaction** — To facilitate is "to allow to happen, to make easy." The facilitator is a gatekeeper, allowing others to speak and then gently closing when a topic is completed. Avoid letting members monopolize "air time." Find ways to limit continual complaining and blaming of others.

**6. Practice Active Listening** — Some people tend to speak rather than listen. Practice and encourage group members to listen, paraphrase, and understand the ideas of others.

**7. Stay With The Speaker** — When one person is discussing a concern or issue, stay with that person until he is finished, rather than allowing other members to take the floor by piggybacking on that person's thoughts.

**8. Stay With The Here And Now** — Deal with what is going on in the lives of the men in attendance. Avoid long stories involving past history or discussing people who are not present.

**9. Summarize The Discussion** — As much as possible, bring ideas together and complete one topic before moving on to another.

**10. Share The Leadership** — A group may learn to fulfill all of the above functions itself. As other group members fulfill facilitator functions, give them the opportunity to do so. This empowers members and spreads the leadership base.

**11. Assist Fathers In Gaining Resources** — Assist the men and their families in learning about children with special needs. Whether it be through referral services, books, pamphlets, videos, or speakers, find places where they can gain knowledge about such topics as advocacy, working with service providers (i.e., schools, hospitals), insurance, trusts, wills and guardianships, supported employment, or respite.

**12. Above All, HAVE FUN!** — Remember that it will take time for the group to grow and develop high levels of trust. Be patient, and never define success by the number of men in attendance; enjoy all those that do participate.





**SERVICE DELIVERY ISSUES IN WORKING WITH FATHERS OF CHILDREN WITH SPECIAL HEALTH NEEDS AND/OR DISABILITIES - CONSIDER:**

- It all starts with ATTITUDE; there must be a willingness to reach out and involve men, even when it seems they are not interested. Have an EXPECTATION that fathers will want to participate in the care and treatment of their children. Talk about families as INTERDEPENDENT: what happens to one affects all family members.
- Assist hospital, clinic, agency and school staff in understanding the vital importance of male INVOLVEMENT in a child's life. Strive to have male STAFF members if at all possible. Men need to see other men providing/modeling caretaking skills. Actively seek and encourage male volunteers.
- Sponsor a staff TRAINING regarding issues of working with fathers. Since hospital, therapy, early intervention and educational staff are predominantly women, assist them to surface their concerns, fears and needs regarding working positively and appropriately with men.
- REVIEW existing programs, from policy to implementation. Examine potential obstacles that limit or stop male involvement. Make sure training materials reflect the message that men are essential members of the family unit and the child's care team. Have men visible in agency, hospital and school videotapes, marketing brochures, parent newsletters. Have a lending library; make available technical or specialized training on videotape so it may be taken home.
- When CONTRACTING with a family, make every effort to have the father available from the very beginning. The longer a man stays away from intervention services (i.e., P.T., O.T., classroom activities), the harder it will be to gain his future participation.
- At INTAKE, gain information about men in the child's life. Discover other male contacts (grandfather, uncle, neighbor, etc.) and find out if they would care to be involved with the child and the services s/he receives. If the father is not living at home, always send materials to both homes. Materials should be written in a style that actively engages men.
- VALUE the problem-solving, pragmatic approach and expertise that many men bring to personal and family concerns. Assist them to find areas where their skills are valued, such as legislative advocacy, building adaptive devices, making videotapes, etc.
- Develop a schedule/program that is RESPONSIVE to a father's concerns. Make appointments with satisfactory lead time so a man may accommodate his work calendar. Consider having early morning, late afternoon or Saturday I.E.P.'s and I.F.S.P.'s.
- Design programs where men SUPPORT other men. Consider such offerings as a Pops 'n Tots activity; father parenting classes; father-to-father support groups; a panel of fathers sharing their expertise on a myriad of service delivery subjects. The essence of support is knowing it is alright to ask for and gain personal resources and assistance.
- Be sensitive and knowledgeable about CULTURAL/RACIAL issues; gain background as to appropriate means for "entering" and "joining" a family. Ask questions, observe and learn about diverse cultures. Avoid letting stereotypes limit a father's involvement with his child.
- Utilize SOCIAL SITUATIONS to introduce fathers to each other, to new concepts, to the idea they are not alone in their needs and concerns. SPONSOR family weekends, potlucks and meetings which encourage and ask for participation of both men and women.

**Now Available  
A Monograph Regarding Fathers**

***Fathers of Children with Special  
Needs: New Horizons***

**James May, M.A., M.Ed.**

The first national publication entirely focused on  
fathers of children with chronic illness or disability. . .  
Information about:

- Research
- New Paradigms for Professionals
- Strategies for Effective Service Delivery
- Developing Support Programs for Fathers
- New Visions for Family-Centered Care
- Resources for Parents and Professionals

\*\*\*\*\*

**Cost: \$6.45 [includes shipping & handling]**

**Available from:**

**Association for the Care of Children's Health  
7910 Woodmont Avenue, Suite 300  
Bethesda, Maryland 20814  
301-654-6549**

## NOW AVAILABLE — A COMPELLING NEW VIDEO

"A moving, sensitive statement about the emotional needs of fathers. It breaks down the old stereotypes that men don't show feelings or nurture their kids: must be seen by all professionals in the field of developmental disabilities" (Earl Brewer, M.D., Director, Kelsey-Seybold Foundation, Houston, Texas)

### "SPECIAL KIDS, SPECIAL DADS - FATHERS OF CHILDREN WITH DISABILITIES"

What does a father experience when his child has a disabling condition? Why does he frequently feel quite isolated? What types of support does he need to bond with his child and deal with the ongoing stresses that exist in his family?

The father of a special needs child is often misunderstood. Because a child typically receives educational and medical services during a father's working hours, dad frequently lacks knowledge about the disability and the interventions available to assist a child's developmental growth. Fathers are rarely seen in the classroom, in conferences or support programs. Yet research reveals that a father often sets the tone for the family in coping with a special needs child. Thus it is imperative we find means for increased involvement of fathers in all aspects of their children's lives.

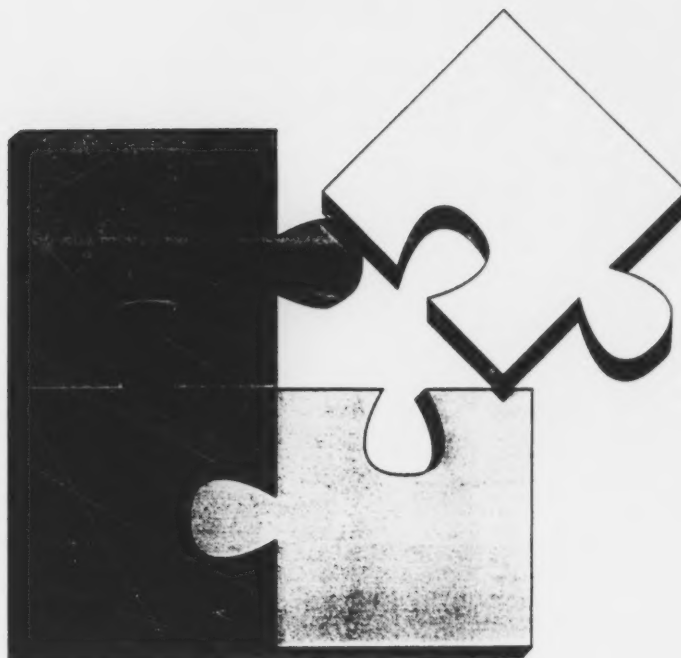
Since 1985, the S.E.F.A.M. Family Support Program, funded by the Office of Maternal and Child Health, has assisted 24 states in developing 39 programs specifically aimed at fathers. This video, the first ever made about fathers of special needs children, and directed by Emmy award winning videographer, David Samuelson, fosters understanding for assisting fathers in parenting their children with disabling conditions. A discussion guide is included.

Length: 23:25 1/2" VHS only  
Cost: \$80.00 Shipping and Handling: \$3.00

"As I have become more involved with fathers of special needs children, I have recognized the tremendous need for and value of forums for fathers to share their despair and hope, sorrow and joy, anger and love, panic and control, responsibility and freedom. Every father should have an opportunity to see this video! This honest confirmation of emotionally involved fathers is a tribute to fatherhood." (Phil Davis, Ph.D., Nevada Association for the Handicapped, Reno, Nevada, father of special needs child)

To order, mail check or money order for \$83.00 made out to: SEFAM Family Support Program, c/o James May, Merrowood School, 16120 N.E. Eighth Street, Bellevue, WA 98008. Sorry no rental or preview videos are available.

## **Maximizing the Helping Relationship: Program Overview**



New York State Department of Health  
Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

## OFFICE OF PUBLIC HEALTH

Lloyd F. Novick, M.D., M.P.H.

Director

Diana Jones Ritter  
Executive Deputy Director

### ***Maximizing the Effectiveness of Helping Partnerships: A Training Program in Cultural Competency***

Program developers: Nina Daratsos, JD, Laura Firmery, MPH, Mary Huber, MA, Michelle Van Ryn, PhD

The Omnibus Budget Reconciliation Act of 1989 (OBRA '89) amendments to Title V of the Social Security Act mandate that programs for children with special health care needs be family centered, community based, culturally competent, and effectively coordinated. These goals are further emphasized in *Healthy People 2000*, Objective 17.20, which calls for an increase in the number of states having service systems for children with special health care needs that are family centered, community based, culturally competent, and effectively coordinated.

To respond to these mandates, the School of Public Health of the University at Albany, State University of New York, in partnership with the Physically Handicapped Children's Program, New York State's Title V Program for Children with Special Health Care Needs, and the SPRANS grant, "Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Care Needs and Their Families," applied for and received a grant from the federal Maternal and Child Health Bureau. The purpose of the grant was to increase the practice of family centered, culturally competent care by service providers who work with families whose children have special health care needs.

This was accomplished by developing a one-day training program for service providers that was tested and evaluated at two sites and is now being delivered statewide.

The following information describes the program:

**STAFF:** The training staff is a mix of parents of children with special needs, most of whom are culturally diverse, and professionals listed above.

#### **TRAINING COMPONENTS:**

The first component presents both theoretical and experiential information on the needs of families who have children with special needs, especially culturally diverse families. This is accomplished through a panel presentation by family members which sets the scene for the issues that will be developed in subsequent sessions throughout the day.

The second component combines lecture, discussion, group brainstorming and problem solving exercises to promote participants' adoption of effective helping attitudes and behavior, the same attitudes and behavior that contribute to culturally competent practice. These include: communicating unconditional positive regard; encouraging client self-disclosure through active listening and engaging in moderate self-disclosure



to reduce social distance. This component is based on extensive research on the role of referent power in maximizing the effectiveness of helping relationships.

The third component reviews the elements of both family-centered and culturally competent service delivery and presents guidelines for the practice of both. Participants assess current practice and brainstorm methods for achieving family-centered, culturally competent services. Topics of cultural competency that are considered include the cultural competence continuum, the role of cultural values and beliefs in accessing health care, and methods for enhancing cultural competency.

In component four, through role plays with the family members, participants rehearse skills that establish an effective, culturally competent, family-centered helping partnership.

#### **PARTICIPANTS:**

Participants are staff from local county health departments who work with the Physically Handicapped Children's Program, the state's Title V Program for Children with Special Health Care Needs, the Early Intervention Program (Part H), the Infant Child Health Assessment Program (Child Find for Part H), migrant health programs, and Early Intervention Service Providers.

#### **EVALUATION:**

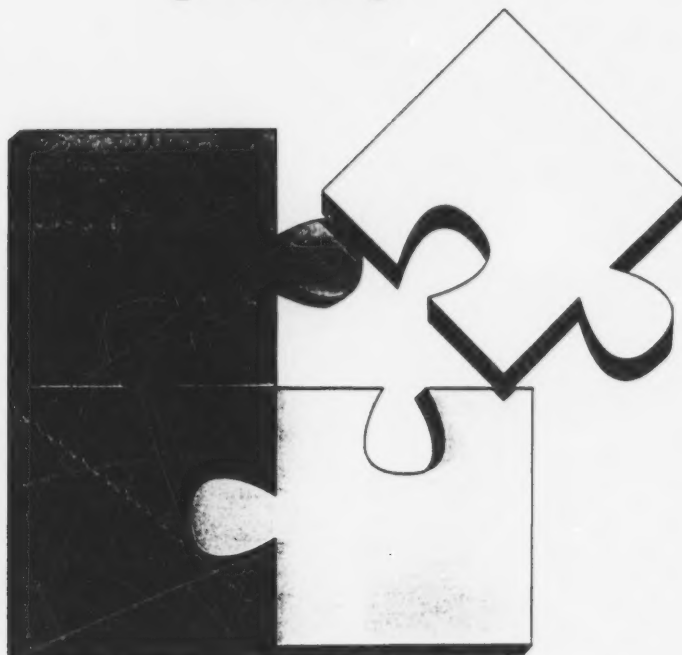
Participants complete a pre-assessment tool, an evaluation immediately at the conclusion of the session, and a post-assessment tool one month after the session.

For additional information, contact:

Mary Huber  
New York State Department of Health  
Corning Tower, Room 208  
ESP  
Albany, NY 12337-0618  
(518) 474-6781



**New York State Directory of  
Self-Help/Mutual Support for  
Children with Special Health  
Needs and Their Families  
(1994)**



New York State Department of Health  
Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower

The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Mart R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Lloyd F. Novick, M.D., M.P.H.  
Director  
Diana Jones Altier  
Executive Deputy Director

May 2, 1994

Dear Colleague:

Enclosed for your information is a copy of the second edition of *The New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families*. The purpose of the *Directory* is to provide a means for families who are caring for a child with special health needs to connect with other families who are experiencing the same situation. Often the most effective help is talking with someone else who is going through the same experience.

We would like to thank those of you who took the time to complete the survey forms for this edition. One hundred additional listings appear this year. Without your help, this document would not be possible. If you know of changes in a current listing, or of networks that should be added, please complete the form on page ii.

The *Directory* is not copyrighted, so please feel free to copy and distribute it broadly. An evaluation form is found on page 79, and your comments are taken seriously. For example, since some families travel out of state for services, this edition contains information on contacts in states close to New York.

Sincerely,

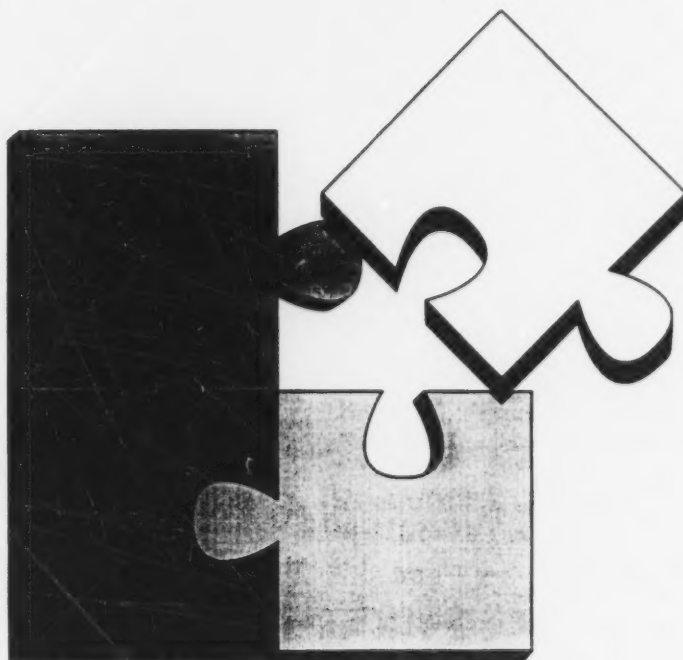
Christopher A. Kus, MD, MPH  
Director  
Bureau of Child and  
Adolescent Health

Mary Huber, MA  
Director  
Family-Professional  
Training Institute

Enclosure

**New York State  
Directory of  
Self-Help/Mutual Support  
for Children with Special  
Health Needs and their Families**

**April 1994**



**New York State Department of Health**

**256**

**Second Edition**

**New York State  
Directory of  
Self-Help/Mutual Support  
for Children with Special  
Health Needs and their Families**

**April 1994**

**Prepared by:**



Westchester Self-Help Clearinghouse  
456 North Street  
White Plains, NY 10605

**Published by:**



New York State Department of Health  
Bureau of Child and Adolescent Health  
Corning Tower - Room 208  
Empire State Plaza  
Albany, NY 12237

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## INTRODUCTION

The New York State Department of Health, Bureau of Child and Adolescent Health, is pleased to present this New York State Directory of Self-Help/ Mutual Support for Children with Special Health Needs and Their Families.

This Directory is one of the activities of a three-year Special Project of Regional and National Significance (SPRANS) grant funded by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services. The project is entitled **Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families**. Its purpose is to empower and strengthen culturally diverse families of children with special health needs to enhance their capacity as caregivers. This is accomplished by linking families to both formal and informal services and support.

Linkages to formal services may take place through the Physically Handicapped Children's Program (PHCP) which is located in each county health unit. PHCP is the State's Children with Special Health Care Needs Program of the Social Security Act, Title V. This program helps eligible families pay for medical care for children with severe, long-term health problems. In addition, in selected counties, PHCP provides case management services. The purpose of this program is to assist families to coordinate a wide range of services they may find useful in caring for their children with special health needs.

**Partners in Health** also provides linkages to informal supports by helping families connect to their peers who are also caring for children with special health needs. Two people or a group of people going through the same experience often provide the most effective help to each other.

This Directory compiles information on self-help/mutual support resources in New York State. Please assist us in updating this list by completing the information form on the next page and returning it to the address provided.

## DIRECTORY INFORMATION FORM

### SELF-HELP/MUTUAL SUPPORT FOR CHILDREN WITH SPECIAL HEALTH NEEDS AND THEIR FAMILIES

If you would like to add a mutual support network to the Directory, or make changes in a current listing, please complete this form.

Date \_\_\_\_\_

- 1) Name of Network \_\_\_\_\_
- 2) Name of Contact Person \_\_\_\_\_
- 3) Address of contact person (May we print the address in the directory? ☐ Yes ☐ No  
Street/City \_\_\_\_\_  
County \_\_\_\_\_
- 4) Phone number of contact person: days ( ) \_\_\_\_\_ eves ( ) \_\_\_\_\_
- 5) Description of network activity: (Please check all that apply.)  
hospital visits ( ) education ( ) advocacy ( ) telephone support ( )  
regular meetings ( ) other (please list) \_\_\_\_\_  
Where (Name of institution or building) \_\_\_\_\_  
Street/City \_\_\_\_\_  
County \_\_\_\_\_ Zip Code \_\_\_\_\_
- 6) Is there a fee or membership dues? ☐ Yes ☐ No \$ \_\_\_\_\_ amount
- 7) Is network leader: a professional ☐ a parent ☐ other (please explain) \_\_\_\_\_
- 8) Who comprises the membership of your network? (e.g., parents, siblings, grandparents, children with the illness)  
\_\_\_\_\_  
\_\_\_\_\_
- 9) Is a language other than English spoken? ☐ Yes ☐ No If yes, please specify: \_\_\_\_\_
- 10) Name and address of person completing this form: \_\_\_\_\_  
Street/City \_\_\_\_\_  
County \_\_\_\_\_  
Zip Code \_\_\_\_\_ Telephone Number ( ) \_\_\_\_\_

Return to:

Mary Huber - NYS DOH  
Corning Tower - Room 208  
Empire State Plaza  
Albany, NY 12237

## WHAT IS SELF-HELP/MUTUAL SUPPORT?

- People with similar experiences and concerns connect with each other for support and information. Friends, extended family members, and others who interact with the family are often involved also.
- A connection may be made in a group, on the phone, or on a one-to-one basis.
- The unique source of help comes from the efforts, skills, knowledge, and experience of other people who share the same situation.
- Participants control the activities.
- Fees or dues, if charged, are minimal.
- Some groups are facilitated by peers; others may have a professional present as a resource.

## WHAT ARE THE BENEFITS OF PARTICIPATING IN SELF-HELP/MUTUAL SUPPORT?

The personal sharing that occurs between people who have "traveled in the same shoes" is the hallmark of the self-help/mutual support process. Participants:

- Feel less isolated and are relieved to discover that others have experienced similar situations.
- Exchange ideas and effective ways to handle problems.
- Actively work to make positive changes in their lives.
- Gain a new sense of control over their lives and feel less overwhelmed by their problems.
- Engage in advocacy and policy making.

Research shows that self-help/mutual support participation substantially improves the quality of life for participants and promotes better health and greater life satisfaction.

Additional information on developing self-help/mutual support is available in the following publication:

Organizing and Maintaining Support Groups for Parents of Children with Chronic Illness and Handicapping Conditions by Minna Newman Nathanson, published in 1986 by the Association for the Care of Children's Health (ACCH). It is available from ACCH, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (301) 654-6549. The cost is \$15.00 plus \$3.50 shipping. The price is discounted for ACCH members and for orders of 10 or more copies.

## ABOUT THE DIRECTORY

The New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families is a listing of self-help/mutual support networks available in New York State. Its primary purpose is to provide a means for families, who are caring for a child with special health needs, to connect with other families who are experiencing the same situation. Special health needs include physically disabling conditions and chronic illnesses.

The Directory is designed to:

- help individuals locate specific networks they may wish to join or call for information;
- assist self-help/mutual support network linkages among different networks;
- provide professionals with a listing of self-help/mutual support available for referral;
- broaden the community's knowledge of the self-help/mutual support movement and of local community-based support networks;
- facilitate linkages between self-help/mutual support networks and professionals;
- document the wide array of services offered by self-help/mutual support including group meetings, one-to-one peer counseling, advocacy, and fund raising.

Sometimes group contact persons or phone numbers change. If you are unable to contact a particular network, have questions about a network, or want help in starting a network, please contact:

Mary Huber  
Project Director  
Partners in Health  
NYS Department of Health  
Corning Tower, Room 208  
Empire State Plaza  
Albany, NY 12237

(518) 474-6781

A listing in the Directory does not imply that the New York State Department of Health or Health Research, Inc. endorse the purpose or ensure the quality of resources described, nor does any omission signify disapproval.

## HOW TO USE THIS DIRECTORY

The New York State Directory of Self-Help/Mutual Support for Children with Special Health Needs and Their Families is divided into several sections. A complete review of all sections may be helpful to locate the most appropriate network or resource. By calling or writing to the contact person, you will be connected to other families who share the same concern as you. If a face-to-face meeting cannot take place, remember that mutual support can take place on the telephone or through letters. The important thing is that people who share the same concerns connect with each other.

- The Directory begins with an alphabetical list of all the self help clearinghouses throughout New York State and in nearby states. They assist people in locating self-help/mutual support for a variety of general concerns. If you do not find the connection you are looking for listed in the Directory, call the self-help clearinghouse.
- Next are listed additional resources including other organizations that can assist families to connect to each other or to obtain information that will help them in caring for their child.
- Following this general listing, the Directory lists support networks for a variety of conditions.
- Each health condition is organized by county, with New York City counties first, followed by an alphabetical listing of other counties in New York State where similar groups exist.
- A listing of all groups *by county* is located at the end of the directory.
- In the appendix is an evaluation form which can provide valuable information to help serve families of children with special health needs.



**NEW YORK STATE LOCAL SELF-HELP  
CLEARINGHOUSES**

For information and referral to the many other support groups available throughout New York State, please contact the local self-help clearinghouses listed below:

**BROOKLYN**

Brooklyn Self-Help Clearinghouse  
30 Third Avenue  
Brooklyn, NY 11217  
(718) 875-1420

**BROOME COUNTY**

Mental Health Association in Broome  
County  
82 Oak Street  
Binghamton, NY 13905  
(607) 771-8888

**CATTARAUGUS COUNTY**

Greater Buffalo Chapter of the  
American Red Cross Olean Branch  
P.O. Box 67  
528 North Barry Street  
Olean, NY 14760  
(716) 372-5800

**CLINTON COUNTY**

CEF Crisis/Helpline  
36 Brinkerhoff Street  
Plattsburgh, NY 12901  
800 DIALSOS (Local)  
(518) 561-2330 (State)

**DUTCHESS COUNTY**

United Way of Dutchess County  
P.O. Box 832  
75 Market Street  
Poughkeepsie, NY 12601  
(914) 473-1500

**ERIE COUNTY**

Erie County Mental Health  
Association  
999 Delaware Avenue  
Buffalo, NY 14209  
(716) 886-1242

**FULTON COUNTY**

HEALTHLINK  
28 South Perry Street  
Johnstown, NY 12095  
(518) 736-1120

**LONG ISLAND**

New York Institute of Technology  
New York College of Osteopathic  
Medicine  
NYCOM 1, 2nd Floor  
Old Westbury, NY 11568  
(516) 686-7444

**MONROE COUNTY**

Mental Health Assoc. of Rochester  
1100 University Avenue  
Rochester, NY 14607  
(716) 256-0590

**MONTGOMERY COUNTY**

St. Mary's Hospital  
Wellness Institute  
427 Guy Park Avenue  
Amsterdam, NY 12010  
(518) 842-1900 ext. 279 or 351

### NEW YORK CITY

New York City Self-Help Center  
120 West 57th Street  
New York, NY 10019  
(212) 586-5770

### NIAGARA COUNTY

Mental Health Association of Niagara  
County  
151 East Avenue  
Lockport, NY 14094  
(716) 433-3780

### ONONDAGA COUNTY

The Volunteer Center  
115 East Jefferson Street  
Suite 400  
Syracuse, NY 13202  
(315) 474-7011

### ORANGE COUNTY

Mental Health Association of Orange  
County  
223 Main Street  
Goshen, NY 10924  
(914) 294-5661

### RENSSELAER COUNTY

Commission on Economic  
Opportunity  
2331 Fifth Avenue  
Troy, NY 12180  
(518) 272-6012

### ROCKLAND COUNTY

Mental Health Association of  
Rockland  
Robert L. Yeager Health Center,  
Bldg. J  
Pomona, NY 10970  
(914) 364-3605

### SARATOGA COUNTY

Mechanicville Area Community  
Service Center, Inc.  
P.O. Box 3 - So. Main Street  
Mechanicville, NY 12118  
(518) 664-8322

### SCHENECTADY COUNTY

INFOLINE of Schenectady County  
152 Barrett Street  
Schenectady, NY 12305  
(518) 374-2244

### STEUBEN COUNTY

HELPLINE  
29 Denison Parkway, East  
Suite B  
Corning, NY 14830  
1 (800) 346-2211  
(607) 936-4114

### SULLIVAN COUNTY

Community General Hospital  
Bushville Road  
P.O. Box 800  
Harris, NY 12742  
(914) 794-3300 ext. 2148

### TOMPKINS COUNTY

Mental Health Association in  
Tompkins County  
Information and Referral Program  
301 South Geneva Street, Rm. G8  
Ithaca, NY 14850  
(607) 273-9250

**ULSTER COUNTY**

Mental Health Association  
Adult Rehabilitation Services  
Building 6  
Willow Park Complex  
Kingston, NY 12401  
(914) 339-9090 ext. 113

**WESTCHESTER COUNTY**

Westchester Self-Help Clearinghouse  
456 North Street  
White Plains, NY 10605  
(914) 949-6301

## CLEARINGHOUSES BORDERING NEW YORK STATE

### CONNECTICUT

Connecticut Self-Help/Mutual  
Support Network  
389 Whitney Avenue  
New Haven, CT 06511  
(203) 789-7645

### NEW JERSEY

New Jersey Self-Help Clearinghouse  
St. Clares-Riverside Medical Center  
Denville, NJ 07834  
(201) 625-9565  
TDD (201) 625-9053

### PENNSYLVANIA

Self-Help Group of Pittsburgh  
1323 Fprbes Avemie. Siote 200  
Pittsburgh, PA 15219  
(412) 261-5363

S.H.I.N.E. (Self-Help Information  
Network Exchange)  
c/o Voluntary Action Center  
Scranton Life Building  
538 Spruce Street., Suite 420  
Scranton, PA 18503  
(717) 961-1234

Self-Help Institute  
462 Monastery Avenue  
Philadelphia, PA 19128  
(215) 482-4316

### VERMONT

Parent to Parent of Vermont  
(Parent Network)  
1 Main Street, #69 Champlain Mill  
Winooski, VT 05404  
(800) 800-4005  
(802) 655-5290

### CANADA

#### MONTREAL

Centre de Reference du Grand  
Montreal  
881 est, boul. de Maisonneuve  
Montreal, Quebec H2L 1Y8  
(514) 527-1375

#### OTTAWA

Self-Help Canada/Entraide Canada  
P.O. Box 64094  
1620 Scott Street  
Ottawa, Ontario K1Y4V1  
(613) 728-1865

#### TORONTO

Self-Help Clearinghouse  
40 Orchard View Boulevard  
Suite 219  
Toronto, Ontario M4R1B9  
(416) 487-4355

## ADDITIONAL RESOURCES

For information about other resources available for families of children with special health needs, contact the organizations listed below:

1. Association for the Care of Children's Health (ACCH) Parent Network  
7910 Woodmont Avenue  
Suite 300  
Bethesda, MD 20814  
(301) 654-6549

ACCH sponsors a Parent Network for parents of children with special needs. The network enables parents to share experiences and expertise in building and strengthening family and community support for their children with special needs.

2. American Airlines - Miles for Kids  
P.O. Box 619688  
Mail Drop 1396  
Dallas - Fort Worth Airport  
Texas 75261-9688  
(817) 963-8118

Miles for Kids will provide transportation for children with medical needs. The child must be under 18 years and the request must come from a non-profit organization which will verify the financial need. If approved, Miles for Kids will provide transportation for the child and both parents.

3. American Self -Help Clearinghouse  
St. Clares - Riverside Medical Center  
Denville, NJ 07834  
(201) 625-7101

The American Self-Help Clearinghouse provides information via its phone service on national and model groups and publishes a national directory of these groups, The Self-Help Sourcebook.

4. CARE FORCE  
P.O. Box 3816  
Humble, TX 77347-3816  
(713) 438-0376

CARE FORCE will provide transportation for children with medical needs upon approval and availability. Limited resources are available for families who have financial needs.

5. Corporate Angel Network, Inc.  
Westchester County Airport  
Building 1  
White Plains, NY 10604  
(914) 329-1313

This is a non-profit organization designed to give cancer patients who require transportation anywhere in the United States the use of available seats on corporate aircraft. There is no financial need criteria. It can be used for cancer treatment, checkup or consultation, not for medical emergency.

6. Genetics Services Program  
NYS Department of Health  
Wadsworth Center for Laboratories  
and Research (WCL&R)  
Empire State Plaza  
Corning Tower, Room E 275  
Albany, NY 12201  
Attention: Katharine Harris  
(518) 474-7148

The New York State Genetics Services Program provides information and referral on genetics support groups and other genetics services.

7. Make-A-Wish Foundation  
575 Madison Avenue  
New York, NY 10022  
(212) 505-WISH

The Make-A-Wish Foundation of America is an organization dedicated to fulfilling the special wishes of children with terminal illness or life-threatening illness. Local chapters exist throughout New York State. For information call (212) 505-WISH.

8. Marty Lyons Foundation  
333 Earle Ovington Boulevard  
Suite 600  
Mitchel Field, NY 11553  
(516) 745-8966

Grants special wishes for children with life-threatening diseases.



9. National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions  
Center for Developmental Disabilities  
School of Medicine, Dept. of Pediatrics  
University of South Carolina  
Columbia, SC 29208  
(800) 922-9234, Ext. 201  
(Voice and TT)

The NIC provides information and referral to appropriate providers of services for families who have infants and young children with disabilities. Information specialists assist families in accessing services such as parent support and training, advocacy, health care, financial resources, assistive technology, early intervention, and other information resources.

10. National Fathers Network  
c/o James May  
16120 N.E. 8th Street  
Bellevue, WA 98008  
(206) 747-4004 or  
(206) 282-1334

The National Fathers Network advocates for fathers and families of children with special needs. Activities include a newsletter, demonstration father support programs and curriculum development on fathers' issues.

11. National Information Center for Children and Youth with Disabilities (NICHCY)  
P.O. Box 1492  
Washington, DC 20013  
(800) 999-5599

NICHCY can provide parents, professionals, and others with information and referral on issues of concern to children and youth with disabilities and their families.

12. National Organization for Rare Disorders (NORD)  
P.O. Box 8923  
New Fairfield, CT 06812-1783  
(203) 746-6518 / (800) 999-NORD

NORD refers people with rare disorders and their families to existing support groups, as well as to individuals and families with similar disorders. Services also include a Rare Disease Database, which can provide reports with up-to-date information on many rare conditions, and a newsletter, Orphan Disease Update.

13. Parent Training and Information Centers:

Advocates for Children of New York, Inc.  
24-16 Bridge Plaza South  
Long Island City, NY 11101  
(718) 729-8866

Parent Network Center  
1443 Main Street  
Buffalo, NY 14209  
(716) 885-1004  
(716) 885-3527 TDD

Resources for Children with Special Needs, Inc.  
200 Park Avenue South, Suite 816  
New York, NY 10023  
(212) 677-4650

Parent Training and Information Centers provide information, referral, advocacy and support to parents and professionals looking for a wide variety of programs and services for children from birth to 21 years old with physical, emotional, learning or developmental disabilities. The New York City office also publishes a resource guide in English and Spanish.

14. Parent-Friend One to One  
New York Easter Seal Society  
845 Central Avenue  
Albany, NY 12206  
Program Coordinator: Linda Rippel  
(800) 727-8785

Parent-Friend provides a support service for parents of a disabled child wishing to speak with another parent whose child has the same disability. Trained volunteer parents representing over 150 disabilities are available. Sponsored by the New York Easter Seal Society.

15. Parents Search or Parents Respond  
"Exceptional Parent"  
209 Harvard Street, Suite 303  
Brookline, MA 02146-5005  
Fax: (617) 730-8742

Parents Search or Parents Respond is a regular section of the magazine, "Exceptional Parent." Readers can exchange information about their practical experience meeting the everyday challenges of life with a child or adolescent with a disability.

16. Physically Handicapped Children's Program  
(800) 522-5006 (Growing Up Healthy Hotline)

The Physically Handicapped Children's Program (PHCP) in New York State helps families pay for medical care for children with severe, long term health problems. Each county has a Physically Handicapped Children's Program. In New York City it is in the Bureau for Families with Special Health Care Needs of the New York City Health Department. To locate the program in your county, call 1-800-522-5006 and ask about the Physically Handicapped Children's Program.

17. Self-Advocacy Training Information and Referral Network (SATIRN)  
NYS Office of Advocate for the Disabled  
Empire State Plaza  
Albany, NY 12223-0001  
(518) 473-4129  
(800) 522-4369 VOICE/TDD  
Hours: 9:00 a.m. - 12:00 Noon, 1:00 p.m. - 4:45 p.m.

SATIRN is a comprehensive database of services for persons with disabilities, their families, and service providers.

18. Starlight Foundation of New York  
1560 Broadway  
Suite 402  
New York, NY 10036  
(212) 354-2878

Grants special wishes to children who are critically, chronically and terminally ill. Referrals may come from doctors and social workers. Requests may be for celebrities, travel or special experiences.

## **AIDS - HIV**

### **New York City**

#### **Bronx**

**Pediatric I.D. Support Group for Caregivers** - 1650 Selwyn Avenue, Apt. 7F, Milstein Building, Bronx, NY 10457

Contact: Adell Harris, MSW (718) 518-5417 - Clinic (718) 518-5402 (Monday and Thursday)

**Support Groups for Foster/Adoptive Parents Caring for HIV+ Children** - (Group conducted in Spanish) Bronx AIDS Services, One Fordham Plaza, Suite 903, Bronx, NY 10458

Contact: Kathy Goodbody (914) 376-4415

#### **Brooklyn**

**Caregivers' Group - Brooklyn Group Support Project** - SUNY Health Science Center, 450 Clarkson Avenue, Brooklyn, NY 11203

Contact: Sheila Crandles (718) 270-2758

**Support Group for Foster/Adoptive Parents Caring for HIV+ Children** - Society for Seamen's Children, 57 Willoughby Street, 3rd Floor, Brooklyn, NY 11201

Contact: Kathy Goodbody (914) 376-4415

#### **Manhattan**

**Support Group for Foster/Adoptive Parents Caring for HIV+ Children** - Cathedral House of St. John the Divine, Amsterdam Avenue, New York, NY 10026

Contact: Kathy Goodbody (914) 376-4415

#### **Queens**

**Support Group for Foster/Adoptive Parents Caring for HIV+ Children** - St. Christopher - Otilie, 89-30 161st Street, 3rd Floor, Queens, NY 11432

Contact: Kathy Goodbody (914) 376-4415

### **Chemung County**

**Southern Tier AIDS Program** - Chemung County Health Department, Heritage Park, John Street, Elmira, NY 14901

Contact: Lisa Lublin (607) 737-2028

### **Montgomery County**

**Centro Civico of Amsterdam, Inc.** - 227 East Main Street, Amsterdam, NY 12010

Contact: Evonne Lomanto (518) 842-3762

**Warren County**

**Positively Pediatrics and Adolescents** - 17 Prospect Drive, Queensbury, NY 12804  
**Contact:** Dianne Donovan (518) 798-8940

**Westchester County**

**Support Group for HIV Positive Parents with HIV Positive Children**  
Project Hope, 1059 Main Street, Peekskill, NY 10566  
**Contact:** Peter Rossi (914) 526-2006

*For additional information on AIDS support groups, contact  
the New York State Department of Health statewide toll free  
number: (800) 541-AIDS.*

**APNEA (INFANT)**

**Nassau County**

**North Shore University Hospital/Infant Apnea Center** - North Shore University  
Hospital-Cornell University Medical College, 300 Community Drive, Manhasset, NY 11030  
**Contact:** Heidi A. Rappa, RN (516) 562-4665



## ARTHRITIS

### New York City

#### **Manhattan**

**Arthritis Foundation - New York Chapter** - 67 Irving Place, New York, NY 10003

Contact: Dorothy Goldstein (212) 477-8310

**Juvenile Arthritis Clinic** - 535 East 70th Street, New York, NY 10021

Contact: Dr. Thomas Lehman (212) 606-1151

#### **Queens**

**Schneider Children's Hospital/Long Island Jewish Medical Center** - 271-16 76th Avenue, New Hyde Park, NY 11042 Attn: Division of Pediatric Rheumatology

Contact: (718) 470-3530

### Suffolk County

**Long Island Chapter of the Arthritis Foundation** - 501 Walt Whitman Road, Melville, NY 11747

Contact: (516) 427-8272

**Young Adult Club of the Arthritis Foundation** - 501 Walt Whitman Road, Melville, NY 11747

Contact: (516) 427-8272

### Westchester County

**Arthritis Foundation, New York Chapter, Childhood Arthritis Support Group**  
785 Mamaroneck Avenue, White Plains, NY 10605

Contact: Barbara Silverstein (914) 683-0842

## ASTHMA

### New York City

#### **Brooklyn**

**American Lung Association of Brooklyn** - 165 Cadman Plaza East, Brooklyn, NY 11201  
Contact: Wendy Iseman (718) 624-8531

#### **Manhattan**

**Family Asthma Program** - New York Lung Association, 432 Park Avenue South, New York, NY 10016  
Contact: Beverly Jones (212) 889-3370

#### **Queens**

**Pediatric Asthma Support Group** - Flushing Hospital Medical Center, 4500 Parsons Boulevard, Flushing, NY 11355  
Contact: Bonnie PELLE (718) 670-5386

**Super Saturday Family Asthma Program** - American Lung Association of Queens, 11225 Queens Blvd., Forest Hills, NY 11375  
Contact: Deidre Boles (718) 263-5656

#### **Staten Island**

**Parents of Asthmatic and Allergic Children** - Staten Island University Hospital - North, 475 Seaview Avenue, Staten Island, NY 10305  
Contact: Josephine Grieco (718) 226-9173

### Nassau County

**Support for Asthmatic Youth** - North Shore University Hospital, 300 Community Drive, Manhasset, NY 11030  
Contact: Renee Theodorakis (516) 625-5735

### Suffolk County

**Support for Asthmatic Youth** - Brookhaven Hospital, 101 Hospital Road, East Patchogue, NY 11772  
Contact: Renee Theodorakis (516) 625-5735

### Wayne County

**Pediatric Pulmonary Program** - Newark-Wayne Community Hospital, Driving Park Avenue, Newark, NY 14513  
Contact: Lisa Rapple (315) 332-2443

**Westchester County**

**Parents of Asthmatic and Allergic Children of Westchester - White Plains  
Hospital Center, Davis Avenue at East Post Road, White Plains, NY 10601**

**Contact: Ruth Stern (914) 681-1078**

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## ATTENTION DEFICIT DISORDER

### Albany County

**Capital District Attention Deficit Disorder Association** - Capital Cablevision,  
Washington Avenue Extension, Albany, NY 12203

Contact: Kathy McArdle (518) 453-0144

### Putnam County

**C.H.A.D.D. (Children With Attention Deficit Disorders)** - Four Winds Hospital  
Conference Center, 800 Cross River Road, Katonah, NY 10536

Contact: C.H.A.D.D. Hotline (914) 278-3012

### Westchester County

**C.H.A.D.D. (Children With Attention Deficit Disorders)** - White Plains Hospital  
Center, Davis Avenue at East Post Road, White Plains, NY 10601

Contact: Barbara du Pont (914) 278-3020

## BLADDER EXSTROPHY

### Westchester County

**Bladder Exstrophy Support Group**

Contact: Steve or Andrea Caris (203) 792-3495

## BRITTLE BONE DISEASE

### Livingston County

**Osteogenesis Imperfecta** - 18 West Street, Nunda, NY 14517

Contact: Lucinda M. Brown (716) 468-2543



## **CANCER**

### **New York City**

#### **Brooklyn**

**Group for Families of Children with Cancer** - University Hospital of Brooklyn, 450 Clarkson Avenue, Brooklyn, NY 11203

Contact: Jennifer Caesar, CSW (718) 270-2005

**I Can Cope** - American Cancer Society, 148 Pierrepont Street, Brooklyn, NY 11201

Contact: Patient Services (718) 237-7850

**Triple C Cancer Coping Club** - Brookdale Hospital Medical Center, Linden Boulevard and Rockaway Parkway, Brooklyn, NY 11212

Contact: Vivian Singer, ACSW (718) 240-5255

#### **Manhattan**

**Cancer Care, Inc.** - 1180 6th Avenue, New York, NY 10036

Contact: Allen Levine (212) 302-2400

**Group for Teenagers (13 - 19)** - Memorial Sloan-Kettering Cancer Center, Pediatric Day Hospital, 5th Floor, 1275 York Avenue, New York, NY 10021

Contact: Nan Beldoch, ACSW (212) 639-7041

**Inpatient Parents Support Group** - Memorial Sloan-Kettering Cancer Center, Dept. of Nursing, 1275 York Avenue, New York, NY 10021

Contact: Shelley McKay, RN (212) 639-6911

**Oncology Support Group** - Babies Hospital, Columbia Presbyterian Medical Center, 620 West 168th Street, New York, NY 10032

Contact: Dr. Anneliese Sitarz (212) 305-2466

**Parent and Family Groups** - Memorial Sloan-Kettering Cancer Center, Pediatric Day Hospital, 5th Floor, 1275 York Avenue, New York, NY 10021

Contact: Nan Beldoch, ACSW (212) 639-7041

**Playgroup For 3-11 Year Olds with Cancer** - Memorial Sloan-Kettering Cancer Center, Pediatric Day Hospital, 5th Floor, 1275 York Avenue, New York, NY 10021

Contact: Nan Beldoch, ACSW (212) 639-7041

### **Albany County**

**Camp Good Days and Special Times** - Trust Company Bank Building, 1084 Madison Avenue, Albany, NY 12208

Contact: Michael Simpson (518) 438-6515

### Broome County

**American Cancer Society** - 57 Front Street, Binghamton, NY 13905

Contact: Marjorie Schreier (607) 722-6471

### Chemung County

**American Cancer Society** - 627 West Church Street, Elmira, NY 14905

Contact: Nancy Kallenborn (607) 734-1552

### Dutchess County

**American Cancer Society** - Hope Lodge, Vassar Brothers Hospital, Reade Place, Poughkeepsie, NY 12601

Contact: Carolyn Heilweil (914) 452-2635

### Erie County

**Camp Good Days and Special Times** - 2440 Sheridan Drive, Suite 401, Tonawanda, NY 14150

Contact: (716) 834-1995

**The Leukemia Society of America, Inc** - 812 Kenmore Avenue, Buffalo, NY 14216

Contact: (716) 875-5400

**Western New York Candlelighters** - Committee of Association for Pediatric Patients, 219 Ehinger Drive, West Seneca, NY 14224

Contact: Joanne Iannello (716) 677-0937

### Monroe County

**American Cancer Society** - 1400 Winton Road North, Rochester, NY 14609

Contact: Terri Kip (716) 288-1950

**Camp Good Days and Special Times** - 1332 Pittsford-Mendon Road, Mendon, NY 14506

Contact: (716) 624-5555

**Cure - Cure Childhood Cancer Association, Inc.** - 840 University Avenue, Rochester, NY 14607

Contact: Donna Pritchard (716) 473-0180

**Parents of Children With Cancer Support Group** - CURE Office, 840 University Avenue, Rochester, NY 14607

Contact: JoAnn Belle-Isle (716) 275-2981

### Nassau County

**Support Group for Young Adults (ages 16-40) with Cancer** - Andrea Hope Olicker Memorial Foundation, Herricks Road Community Center, Herricks Road, New Hyde Park, NY 11040

Contact: Sydell Olicker (516) 747-3553

**The Candlelighters Childhood Cancer Foundation of Long Island** - 41 Spruce Street, New York, NY 11751

Contact: Bob and Peggy Norton (516) 277-2173

### Niagara County

**American Cancer Society** - 345 Third Street, Suite 560, Box 314, Bridge Station, Niagara Falls, NY 14305

Contact: Fonda Hayes (716) 284-4084

### Onondaga County

**Adolescent Support Group** - Ronald McDonald House of Central NY

Contact: Mark Clauss, CSW (315) 464-5294

**Camp Good Days and Special Times** - 404 Oak Street, Syracuse, NY 13203

Contact: (315) 426-0736

**PROP (Parents Reach-Out Program)** - SUNY Health Science Center, 750 East Adams Street, Syracuse, NY 13210

Contact: Mark Clauss (315) 464-5294

### Suffolk County

**The Candlelighters Childhood Cancer Foundation of Long Island** - 41 Spruce Street, New York, NY 11751

Contact: Bob and Peggy Norton (516) 277-2173

## CELIAC SPRUE

### New York City

#### **Staten Island**

**Staten Island Celiac Society** - 85 Cloverdale Avenue, Staten Island, NY 10308

Contact: Lila T. Barbes (718) 984-8547

#### **Erie County**

**Celiac Sprue Association** - P.O. Box 611, East Aurora, NY 14052

Contact: Joanne E. Hameister (716) 655-0849

#### **Monroe County**

**Lilac Celiacs** - Strong Memorial Hospital, 601 Elmwood Avenue, Room 2-8513,  
Rochester, NY 14642

Contact: Karen Meyers (716) 671-1915

#### **Westchester County**

**Westchester Celiac Sprue Support Group** - Phelps Memorial Hospital Center, 701  
North Broadway, North Tarrytown, NY 10591

Contact: Sue Goldstein (914) 428-1389

## **CEREBRAL PALSY**

### **New York City**

#### **Bronx**

**United Cerebral Palsy/NYC Children's Programs** - 1770 Stillwell Avenue,  
Bronx, NY 10469

Contact: Beverly Ellman (718) 652-9790

#### **Brooklyn**

**United Cerebral Palsy/NYC Children's Programs** -160/175 Lawrence Avenue,  
Brooklyn, NY 11230

Contact: Karen Samet (718) 436-7600

#### **Manhattan**

**United Cerebral Palsy/NYC Children's Programs** - 120 East 23rd Street, New  
York, NY 10010

Contact: Robin Angel (212) 677-7400

#### **Staten Island**

**Parent to Parent New York, Inc.** - Institute for Basic Research, 1050 Forest Hill  
Road, Staten Island, NY 10314

Contact: Marie Goepel (718) 983-5272

**United Cerebral Palsy/NYC Children's Programs** - 281 Port Richmond Avenue,  
Staten Island, NY 10302

Contact: Janet Killeen (718) 442-6006

#### **Fulton County**

**United Cerebral Palsy of Fulton and Montgomery Counties** - 67 Division  
Street, P.O. Box 466, Amsterdam, NY 12010

Contact: Cindy Kuzia, RN (518) 842-3511

#### **Montgomery County**

**United Cerebral Palsy of Fulton and Montgomery Counties** - 67 Division  
Street, P.O. Box 466, Amsterdam, NY 12010

Contact: Cindy Kuzia, RN (518) 842-3511

## **CHRONIC ILLNESS**

### **New York City**

#### **Brooklyn**

**Nachos Healthnet** - 1310 48th Street, Brooklyn, NY 11219

**Contact:** Rabbi Pinchos D. Horowitz (718) 436-7373

**Parent to Parent Network of Brooklyn**

**Contact:** Paul Martin (718) 284-4064

#### **Manhattan**

**CHAI Lifeline** - 48 West 25th Street, 6th Floor, New York, NY 10010

**Contact:** Esther Schwartz (212) 255-1160

**S.K.I.P. (Sick Kids Need Involved People) of New York, Inc.**

545 Madison Avenue, 13th Floor, New York, NY 10022

**Contact:** Margaret Mikol (212) 421-9160

### **Allegany County**

**Parent Support Group** - Various locales in Wellsville

**Contact:** Patricia Maiden (716) 593-5178 or

Carol Cosgrove (716) 268-9263

### **Cattaraugus County**

**American Red Cross Self-Help Clearinghouse** - 528 North Barry Street,  
P.O. Box 67, Olean, NY 14760

**Contact:** Linore E. Lounsbury (716) 372-5800

### **Clinton County**

**Parents of Special Needs Children** - Board of Cooperative Educational Services  
(BOCES), Route 3, Plattsburgh, NY 12901

**Contact:** Kathleen Tallon (518) 561-0900 (day)

David Desjardins (516) 566-8236 (evening)

### **Chautauqua County**

**See Erie County:** Support Group for Families Who Have Children with Down  
Syndrome and/or Other Handicapping Conditions

### **Cortland County**

**The Fathers Network of Cortland County** - The Special Children's Center, 882  
NYS Route 13, Cortland, NY 13045

**Contact:** David Weinstein (607) 753-9375



**The Inclusion Network of Cortland County, Inc. - The Special Children's Center, 882 NYS Route 13, Cortland, NY 13045**  
**Contact:** Annemarie Mamison (607) 753-9375

**Erie County**

**Parent Network of Western New York, Inc. - 1443 Main Street, Buffalo, NY 14209**  
**Contact:** Joan Watkins (716) 885-1004

**S.K.I.P. (Sick Kids Need Involved People) of New York, Inc. 28 Jeffrey Drive, Depew, NY 14043**  
**Contact:** (716) 681-1307

**Support Group for Families Who Have Children with Down Syndrome and/or Other Handicapping Conditions - League for the Handicapped, Pre-School Learning Center, 393 North Street, Springville, NY 14147**  
**Contact:** Lorraine Blum (716) 457-3567

**Genesee County**

**Parent Advocate - 8319 East Main Road, LeRoy, NY 14482**  
**Contact:** Ann L. Scherff (716) 768-2759

**Monroe County**

**S.K.I.P. (Sick Kids Need Involved People) of New York - c/o Monroe D.D.S.O., 1050 University Avenue, Rochester, NY 14607**  
**Contact:** Barbara Van Herreweghe (716) 256-5332

**Montgomery County**

**Independent Living Center of Amsterdam, Inc. - 12 Chestnut Street, Amsterdam, NY 12010**  
**Contact:** Bonnie Page (518) 842-3561

**Nassau County**

**Parent Information Group - North Shore University Hospital, Child Development Center, 444 Community Drive, Manhasset, NY 11030**  
**Contact:** Patricia Weiner (516) 365-3860

**The New Survivors**  
**Contact:** Donna Appell (516) 599-2077

**Onondaga County**

**Support Group for Parents of Critically/Chronically Ill Children**

Contact: Diane Alciati or Sue Crichton (315) 446-4692

**Otsego County**

**Parent Support Network** - Oneonta Day Treatment Center, Lower River Street,  
Oneonta, NY 13820

Contact: Kathleen Wenck (607) 432-2421

**Rockland County**

**S.A.F.E.R. (Support, Advocate, Facilitate, Educate, Respect)** - New City  
Library, Main Street, New City, NY 10956

Contact: Jan Kochmeister (914) 639-9313

**Suffolk County**

**Little Angel Fund**

Contact: Jenny Tranfaglia (516) 736-2512

**The New Survivors**

Contact: Carolyn Leitke (516) 758-2101

**Westchester County**

**Westchester Advocates for Medically Fragile and/or Technology Dependent  
Children and Their Families** - Richmond Children's Center, 919 North Broadway,  
Yonkers, NY 10701

Contact: Carol Baron (914) 968-1900

**Wyoming County**

**See Erie County:** Support Group for Families Who Have Children with Down  
Syndrome and/or Other Handicapping Conditions

## **CLEFT PALATE**

### **Broome County**

**Cleft Lip and Palate Family Support Group** - Handicapped Children's Association,  
18 Broad Street, Johnson City, NY 13790

**Contact:** Debbie Sturdevant (607) 692-4353 or Bob Abbey (607) 754-4175

### **Nassau County**

**AboutFace, Long Island** - East Meadow Library, East Meadow, NY 11554

**Contact:** Sue Mundy (516) 826-3452 or Irv Fischer (800) 676-5727

**Cleft Lip, Cleft Palate Adolescent Support Group** - East Meadow Library, East Meadow, NY 11554

**Contact:** Donna Donatelli, CSW (516) 562-4637

### **Suffolk County**

**Suffolk Cleft Palate Association** - St. Charles Hospital, Port Jefferson, NY 11776

**Contact:** Milton Tuerk, MD, DDS (516) 475-1390

## COMA RECOVERY

### Nassau County

Coma Recovery Association - South Nassau Communities Hospital, Oceanside, NY  
11572.

Contact: Florence Manginaro (516) 486-2847

## COMMUNICATION DISORDERS

### Albany County

**Council of Children and Teenagers Who Stutter**

Contact: Sister Charleen Bloom (518) 454-5122

### Westchester County

**Donald Reed Speech Center - Donald Reed Speech Center, 701 No. Broadway,  
North Tarrytown, NY 10591**

Contact: Dr. Judith Christopher (914) 366-3000 ext. 4660

## COOLEY'S ANEMIA

### New York City

#### Manhattan

**Thalassemia Action Group** - Cooley's Anemia Foundation, 105 East 22nd Street, Suite 911, New York, NY 10010

Contact: 800-522-7222

#### Monroe County

**Cooley's Anemia Foundation (Thalassemia)**

Contact: Mary Siconolfi (716) 288-4431 after 4 p.m.

#### Nassau County

**Cooley's Anemia Support Group** - Nassau County Medical Center/Pediatric Hematology Division, 2201 Hempstead Turnpike, East Meadow, NY 11554

Contact: Dr. Dominick Sabatino or Barbara Shotter, RN (516) 542-5798 or (516) 542-2177



## **CRANIO-FACIAL**

### **New York City**

#### **Manhattan**

**Forward Face** - Institute for Reconstructive and Plastic Surgery, New York University,  
317 East 34th Street, Suite 901, New York, NY 10016  
**Contact:** (800) 422-FACE

#### **Broome County**

**United Health Services Hospitals Cleft and Cranio-Facial Care Team**  
United Health Services Hospitals, 33-52 Harrison Street, Johnson City, NY 13790  
**Contact:** Elizabeth M. Pulse or Becky Earley (607) 763-6666

## **CROHN'S DISEASE**

### **New York City**

#### **Brooklyn**

**SUNY Health Science Center Brooklyn Support Group for Children with Inflammatory Bowel Disease**

**Contact:** Dr. Simon Rabinowitz (718) 270-1647

#### **Manhattan**

**Ileostomy Association of New York - American Cancer Society, 19 West 56th Street, New York, NY 10019**

**Contact:** (212) 864-1968

**Support Group for Families of Children with Crohn's Disease and Ulcerative Colitis - Crohn's and Colitis Foundation of America, 386 Park Avenue So., 14th Floor, New York, NY 10016**

**Contact:** Joan Telley (212) 679-1570

**Support Group for Parents of Children with Inflammatory Bowel Disease Mt. Sinai Medical Center, 1 Gustave Levy Place, New York, NY 10029**

**Contact:** Bambi Fisher, CSW (212) 241-9113

### **Albany County**

**Crohn's and Colitis Foundation of America - 4 Normanskill Boulevard, Delmar, NY 12054**

**Contact:** Pearl Mandel (518) 439-0252

### **Nassau County**

**Reach Out for Youth with Ileitis and Colitis, Inc. - North Shore University Hospital, 300 Community Drive, Manhasset, NY 11030**

**Contact:** Susan Spellman (516) 822-8010

**Support Group for Families and Children with Crohn's Disease and Ulcerative Colitis - Schneider Children's Hospital, 269-01 76th Avenue, New Hyde Park, NY 11042**

**Contact:** Dr. Jeremiah Levine or Kathryn Moschetto, RN (718) 470-3430

### **Westchester County**

**Support Group for Parents of Children with Inflammatory Bowel Disease Westchester Office of Pediatric Gastroenterology, Division of Mt. Sinai Medical Center, 147 Underhill Avenue, White Plains, NY 10604**

**Contact:** Bambi Fisher, CSW (212) 241-9113

## CA CYSTIC FIBROSIS

### New York City

#### Manhattan

##### **Cystic Fibrosis Foundation**

**Contact:** Ann Steffen (212) 986-8783

**Parent Support Group** - Cystic Fibrosis Center, St. Vincent's Hospital, 36 7th Avenue, Suite 509, New York, NY 10011

**Contact:** Lisa Sobelsohn, CSW, BCD (212) 604-8897

#### Staten Island

**Staten Island Cystic Fibrosis Circle** - Institute for Basic Research, 1050 Forest Hill Road, Staten Island, NY 10314

**Contact:** Maureen Marlow (718) 447-2535

#### Erie County

**Cystic Fibrosis Parent Support Group** - Children's Hospital of Buffalo, Lung Center, 219 Bryant Street, Buffalo, NY 14222

**Contact:** Mary M. Kontos, PNP or Kimberly Rand, MSW (716) 878-7524

#### Monroe County

**Cystic Fibrosis Family Connection** - P.O. Box 93328, Rochester, NY 14692

**Contact:** Sue (716) 334-6563 or Valerie Davis (716) 352-9491

#### Westchester County

**Support Group for Parents of Young Children with Cystic Fibrosis**  
Munger Pavilion, Room 106, New York Medical College, Valhalla, NY 10595

**Contact:** Rose Murray (914) 285-7585

## **DIABETES**

### **New York City**

#### **Bronx**

**Juvenile - Parent Support Group** - Montefiore Medical Center, 111 East 210th Street, Silver Zone, 4th floor classrooms B & C, Bronx, NY 10467

**Contact:** Leonor Aponte (718) 920-7446

#### **Manhattan**

**Parents Support Group for Parents with Young Children with Diabetes**

Mt. Sinai Medical Center, 1 Gustave Levy Place, New York, NY 10029

**Contact:** Melissa Strugger, CSW (212) 241-6936

#### **Queens**

**Support Group for Parents of Children with Diabetes** - Schneider Children's Hospital, 270-05 76th Avenue, New Hyde Park, NY 11042

**Contact:** Barbara Ryan, RN (718) 470-3289

#### **Staten Island**

**St. Vincent's Juvenile/Parent's Group**

**Contact:** George Paulsen (718) 876-2100

### **Erie County**

**Juvenile Diabetes Foundation** - 442 Beach Road, Buffalo, NY 14225

**Contact:** Mary Miranda (716) 632-2873

### **Monroe County**

**American Diabetes Association** - 1650 Elmwood Avenue, Rochester, NY 14620

**Contact:** Beverly Gaines (716) 271-1260

**Parent/Youth Support Group** - Al Sigl Center, 1000 Elmwood Avenue, Rochester, NY 14620

**Contact:** Beverly Gaines (716) 271-1260

**Type I Diabetes Support Group** - American Diabetes Association, 1650 Elmwood Avenue, Rochester, NY 14620

**Contact:** Beverly Gaines (716) 271-1260

### Nassau County

**Adolescent Group for Teens with Diabetes** - North Shore University Hospital, Pediatric Endocrinology Department, 9th Floor - Tower Building, 300 Community Drive, Manhasset, NY 11030

Contact: Jean Corrigan (516) 562-4635

**Juvenile Diabetes Foundation** - 93 Main Street, Port Washington, NY 11050

Contact: Faye Rokhsar (516) 944-3622

**Juvenile Diabetes Foundation Support Group** - The Juvenile Diabetes Foundation, 93 Main Street, Port Washington, NY 11050

Contact: Eileen Flax (516) 921-0787

### Oneida County

**American Diabetes Association, Central New York Chapter**

Contact: Sylvia M. Hough (315) 735-0591

### Schenectady County

**Sugar Free Gang** - Ellis Hospital, 1101 Nott Street, Schenectady, NY 12308

Contact: Joanne DeNovio, RN (518) 382-4138

### Suffolk County

**Families with Children Who Have Diabetes** - Connetquot Public Library, 760 Ocean Avenue, Bohemia, NY 11716

Contact: Joan Tisdale (516) 567-6024

**Families with Children Who Have Diabetes** - Mastic-Moriches Shirley Library, 301 William Floyd Parkway, Mastic, NY 11950

Contact: Pam Barci (516) 395-9509

**Juvenile Diabetes Foundation** - 93 Main Street, Port Washington, NY 11050

Contact: Faye Rokhsar (516) 944-3622

### Sullivan County

**Diabetes Support Group** - Community General Hospital of Sullivan County, Box 800, Bushville Road, Harris, NY 12742

Contact: Susan Eronymous (914) 794-3300 ext. 2148

### Westchester County

**Parent-Child Diabetes Support Group** - American Diabetes Association, 100 Clearbrook Road, Elmsford, NY 10523

Contact: Carolyn Tujague (914) 345-9300

## DOWN SYNDROME

### New York City

#### **Brooklyn**

**Project H.O.P.E., Ltd.** - 8206 15th Avenue, Brooklyn, NY 11228

Contact: Jean Giannone (718) 331-9006

**New York League for Early Learning, Inc.** - 420 95th Street,  
Brooklyn, NY 11209

Contact: Elaine Gregoli (718) 680-9751

#### **Manhattan**

**Down Syndrome Support Group of Manhattan** - 301 East 87th Street, Apt. 12D,  
New York, NY 10128

Contact: Kathy Hanlon (212) 831-5439

**The Cooke Foundation for Special Education** - 456 West 52nd Street, New York,  
NY 10019

Contact: Dr. Frances D. Mayer (212) 245-3376

#### **Queens**

**Down Syndrome Parents Groups of Queens** - Box 81, Ozone Park, NY 11417

Contact: Linda Glazebrook - Write to above address for information

**Down Syndrome Parent Support Group of Queens** - 209-14 82nd Avenue, Hollis  
Hills, NY 11427

Contact: Elizabeth Harris (718) 465-6261

### Albany County

**Down Syndrome-Aim High, Inc.** - P.O. Box 12-624, Albany, NY 12212

Contact: Kathy Malinowski (518) 439-6038

### Broome County

**Parents of Children with Down Syndrome Support Group** - 305 Main Street,  
Binghamton, NY 13905

Contact: Mary McKilligan (607) 729-1295

### Cattaraugus County

**Down Syndrome Support Group of Cattaraugus County** - P.O. Box 1015,  
Olean, NY 14760

Contact: Julie A. Stavish (716) 373-3026



### **Chautauqua County**

**See Erie County:** Support Group for Families Who Have Children with Down Syndrome and/or Other Handicapping Conditions

### **Dutchess County**

**Mid Hudson Valley Down Syndrome Congress** - 14 Zerner Boulevard, Hopewell Junction, NY 12533

**Contact:** Al Maratta (914) 226-5220

### **Erie County**

**Down Syndrome Parent Group of Western New York** - 547 Englewood Avenue, Kenmore, NY 14223

**Contact:** Carol A. Hetzelt (716) 832-9334

**Support Group for Families Who Have Children with Down Syndrome and/or Other Handicapping Conditions** - League for the Handicapped, Pre-School Learning Center, 393 North Street, Springville, NY 14147

**Contact:** Lorraine Blum (716) 457-3567

### **Essex County**

**Early Intervention Program Essex County ARC** - Port Henry, NY 12997

**Contact:** Barbara Reed (518) 546-3355

### **Genesee County**

**Down Syndrome Parents Support Group of Genesee County, Inc.** - 3770 Pike Road, Batavia, NY 14020

**Contact:** Kay Cook (716) 344-2092

### **Monroe County**

**Flower City Down Syndrome Network** - 80 Karlan Drive, Rochester, NY 14617

**Contact:** Laura Khederian (716) 338-2101

### **Nassau County**

**Association for Children with Down Syndrome** - 2616 Martin Avenue, Bellmore, NY 11710

**Contact:** Fredda Stimell (516) 221-4700

**Down Syndrome Parents Group** - Nassau County Medical Center/Child Development Division, 2201 Hempstead Turnpike, East Meadow, NY 11554

**Contact:** Jack Sherman, MD (516) 542-3391

### Onondaga County

Down Syndrome Association of Central New York - 4327 Forestbrook Drive,  
Liverpool, NY 13090

Contact: Fran Buckley (314) 622-1378

Down Syndrome Association of Central New York - P.O. Box 5,  
Manlius, NY 13104

Contact: Shari Bottego (315) 637-9711 or (315) 682-4289

### Orange County

Mid Hudson Valley Down Syndrome Congress - 701 North Street,  
Middletown, NY 10940

Contact: Emy O'Connell (914) 342-3790

### Orleans County

Parents Through the Years - Orleans ARC, Box 439, Albion, NY 14411

Contact: Emma Perkins - Write to above address for information

### St. Lawrence County

Down Syndrome Awareness Group - Down Syndrome Association of St. Lawrence  
County, P.O. Box 391, Canton, NY 13617

Contact: Jackie Sauter (315) 386-2018

### Suffolk County

Down Syndrome Parent Support Group of Long Island - 31 Charm City Drive,  
Port Jefferson Station, NY 11776

Contact: Mary Kurlowicz (516) 474-1879

Down Syndrome Parent Support Group of Long Island - P.O. Box 287, East  
Setauket, NY 11733

Contact: Lisa Campbell (516) 696-0564

### Ulster County

Mid Hudson Valley Down Syndrome Congress, Inc. - Route 1, Box 224, Grist  
Mill Road, Tillson, NY 12486

Contact: David Wurtz (914) 658-8419

### Washington County

Down Syndrome Group - 18 Williams Street, Hudson Falls, NY 12839

Contact: Kathy Gaulin (518) 747-0672

**Westchester County**

**Down Syndrome Adoption Exchange - 56 Midchester Avenue,  
White Plains, NY 10606**

**Contact: (914) 428-1236**

**Parent Assistance Committee on Down Syndrome - Westchester ARC,  
74 Westmoreland Avenue, White Plains, NY 10606**

**Contact: ARC (914) 428-8330 or Barbara Levitz (914) 739-4085**

**Wyoming County**

**See Erie County: Support Group for Families Who Have Children with Down  
Syndrome and/or Other Handicapping Conditions**

## DYSTONIA

### Albany County

**Dystonia Support Group**

Contact: Rita LoGuidice (518) 459-6663

## **EPILEPSY**

### **New York City**

#### **Brooklyn**

**Epilepsy Institute** - c/o L.I.C.H. The Othmer Building, Neurology Department, Room 327, Brooklyn, NY 11201

**Contact:** Pamela Conford, CSW (718) 802-0770

#### **Manhattan**

**Epilepsy Institute** - 257 Park Avenue South, 3rd Floor, New York, NY 10010

**Contact:** Pamela Conford (212) 677-8550

**Epilepsy Society of New York City** - 305 7th Avenue, New York, NY 10001

**Contact:** Patricia Niego (212) 633-2930

### **Albany County**

**Epilepsy Association of the Capital District** - Bethlehem Town Library, 451 Delaware Avenue, Delmar, NY 12054

**Contact:** Jeannine White (518) 456-7501

### **Erie County**

**Epilepsy Parent and Family Network of Western NY** - Epilepsy Association of Western New York, 339 Elmwood Avenue, Buffalo, NY 14222

**Contact:** Barbara Brossard, CRC (716) 883-5396

### **Nassau County**

**Parent Support Group** - Epilepsy Foundation, 550 Stewart Avenue, Garden City, NY 11530

**Contact:** Nicole Brill, CSW (516) 794-5500

### **Rockland County**

**Epilepsy Society of Southern New York, Inc.** - 4 Secor Road, Box 371, Thiells, NY 10984

**Contact:** Carol Solomon (914) 942-0002

### **Westchester County**

**Epilepsy Institute** - Mt. Vernon Hospital, 12 North 7th Avenue, Mt. Vernon, NY 10550

**Contact:** Phyllis Beinstein (914) 664-6008

## GENETIC DISORDERS

### New York City

#### Manhattan

**LIFESTART Program-** Lenox Hill Hospital, 100 East 77th Street,  
New York, NY 10021

Contact: Hilda Chusid, CSW (212) 434-2279

#### Erie County

**Turners Syndrome Support Group**

Contact: Wanda Grandner (716) 878-7588

#### Monroe County

**Support Organization for Trisomy 18, 13 and Related Disorders -** 2982 South  
Union Street, Rochester, NY 14624

Contact: Barbara Vanterreweghe (716) 594-4621

#### Westchester County

**Velo-Cardio-Facial Syndrome Association (Shprintzen Syndrome)**

Blythdale Children's Hospital, Bradhurst Avenue (Route 100), Valhalla, NY 10595

Contact: Judy Ziet (718) 261-8049

## OTHER GENETIC DISORDERS

The following genetic disorders are not listed under individual headings. For information about current or emerging groups for these and other genetic disorders please contact:

NY State Genetic Services Program  
NY State Department of Health  
Wadsworth Center for Laboratories and Research  
Empire State Plaza  
Corning Tower Room E275  
Albany, NY 12201

Attention: Katharine Harris or Karen Greendale (518) 486-2215

Association for Children with Russell-Silver Syndrome

Association for Glycogen Storage Disease

Canavan Foundation

Charcot-Marie Tooth Association



Chromosome Deletion Outreach  
 Cystinosis Foundation, Inc.  
 Developmental Disabilities Prevention Program  
 Dysautonomia Foundation, Inc.  
 Dystrophic Epidermolysis Bullosa Research Association of America, Inc.  
 Families of Spinal Muscular Atrophy  
 Fanconi's Anemia Research Fund Support Group  
 FIRST - Foundation for Ichthyosis and Related Skin Types  
 Fragile X Association of New York, Inc.  
 Guardians of Hydrocephalus Research Foundation  
 Hemochromatosis Research Foundation  
 Hereditary Hemorrhagic Telangiectasia Foundation International  
 Huntington's Disease Society of America, Inc.  
 Huntington's Disease Support Group  
 Immune Deficiency Foundation  
 Iron Overload Diseases Association  
 Laurence-Moon-Biedl Syndrome  
 Lowe's Syndrome Association  
 Malignant Hyperthermia Association of the United States  
 Maple Syrup Urine Disease  
 Mucopolidosis IV Foundation  
 Myelomeningocele Parent Support Group  
 Myoclonus Families United  
 Narcolepsy and Cataplexy Foundation of America  
 Narcolepsy Network  
 National Ataxia Foundation  
 National Congenital Port Wine Stain Foundation  
 National Foundation for Facial Reconstruction  
 National Foundation for Jewish Genetic Diseases  
 National Foundation for Pseudoxanthoma Elasticum  
 National Gaucher's Disease Foundation  
 National Growth Foundation  
 National Mucopolysaccharidosis Society, Inc.  
 National Organization for Albinism and Hypopigmentation (NOAH)  
 National Tay-Sachs and Allied Diseases Association  
 National Tuberous Sclerosis Association  
 Osteogenesis Imperfecta Foundation  
 Parents Accepting Their Children's Health (PATCH)  
 Polycystic Kidney Research Foundation  
 Pseudohypoparathyroidism Self-Help Clearinghouse  
 Retinitis Pigmentosa Foundation  
 Share and Care (Cockayne's Syndrome)  
 Special Handling of Handicapped Children  
 Support Group for Monosomy 9p  
 Tay-Sachs Association  
 Thrombocytopenia/Absent Radius Syndrome Association  
 VHL (Von Hippel-Lindau) Family Alliance  
 Williams Syndrome Association

## HEAD INJURY

### Albany County

NYS Head Injury Association, Inc. - 855 Central Avenue, Albany, NY 12206

Contact: (800) 228-8201

### Otsego County

Bassett Hospital Head Injury Support Group - Bassett Hospital, Atwell Avenue,  
Cooperstown, NY 13326

Contact: Debra A. Wolff (607) 547-6912

### Westchester County

Westchester/Putnam Chapter, NYS Head Injury Association - Burke  
Rehabilitation Center, 785 Mamaroneck Avenue, White Plains, NY 10605

Contact: Donna Russo (914) 948-0050 ext. 2334

## HEARING

### New York City

#### Manhattan

**New York League for the Hard of Hearing** - 71 West 23rd Street, New York, NY 10010

Contact: Dorene Watkins (212) 741-6068

#### Queens

**Acoustic Neuroma Association**

Contact: Sheldon Raskin (718) 886-4803

**Lexington School for the Deaf** - 30th Avenue and 75th Street, Jackson Heights, NY 11370

Contact: Dr. Oscar Cohen (718) 899-8800 ext. 209

### Albany County

**Parents of Deaf and Hard of Hearing Children**

Contact: Ann Gainer (518) 861-8522

### Chautauqua County

**Chautauqua Hear** - R.D.#1, 1201 Bunce Road, Frewsburg, NY 14738

Contact: Sue Sehl (716) 782-4934

### Erie County

**Self-Help for Hard of Hearing - Western New York Chapter** - St. Stephen's Bethlehem United Church of Christ, 750 Wehrle Drive, Buffalo, NY 14225

Contact: Don Van Auken (716) 895-1093

### Oneida County

**Deaf Infant Parent Support Group** - Faxton Hospital, 1676 Sunset Avenue, Utica, NY 13502

Contact: Jane M. Waligora (315) 738-6455

### Rockland County

**Rockland County Association for the Hearing Impaired** - Jawonio, 260 Little Tor Road, New City, NY 10956

Contact: Suzanne Mackey (914) 634-4745

**Westchester County**

**Group for Parents of Hearing Impaired Children - Burke Rehabilitation Center,  
785 Mamaroneck Avenue, White Plains, NY 10605**

**Contact: Shelly Shotland or Sandy Solomon (914) 949-0034**

## HEART

### Albany County

**Parents and Cardiac Children Together - Telephone Network**

Contact: Joan Clifford (518) 869-1961

### Erie County

**Heart Parents Association of Children's Hospital - Children's Hospital of Buffalo, 219 Bryant Street, Buffalo, NY 14222**

Contact: John Parker (716) 684-3761

### Nassau County

**Big Hearts for Little Hearts - American Heart Association, Inc., Nassau Chapter, 365 Willis Avenue, Mineola, NY 11501**

Contact: Edward Webb (516) 741-5522

### Rockland

**P.A.C.C.T. (Parents and Cardiac Children Together)**

Contact: Allis Dunlavey (914) 623-0008

### Westchester County

**P.A.C.C.T. (Parents and Cardiac Children Together) - American Heart Association, 3020 Westchester Avenue, Purchase, NY 10577**

Contact: Nancy Schiff (914) 999-4370

## HEMOPHILIA

### Broome

**Hemophilia/Blood Coagulation Disorder Support Group**

Contact: Doris Michalovic (607) 763-6436

### Erie County

**Parent Support Group** - Children's Hospital of Buffalo, 219 Bryant Street, Buffalo, NY 14222

Contact: Lynn Menza, RN (716) 878-7446

**SHARE (Supporting Hemophiliacs and Responding Effectively)** - Hemophilia Center of Western New York, 219 Bryant Street, Buffalo, NY 14222

Contact: Lynn Menza (716) 878-7446 or Mary Haggerty (716) 838-8433



## HYDROCEPHALY

Nassau County

**Guardians of Hydrocephalus**

Contact: (516) 735-3247

## **INFANT BEREAVEMENT**

### **New York City**

#### **Queens**

**Bereavement Support Group for Parents Who Have Experienced Infant Death** - Schneider Children's Hospital, Long Island Jewish Medical Center, New Hyde Park, NY 11042

Contact: Mona S. Bokat, ACSW (718) 470-3443 or (718) 470-3124

#### **Erie County**

**SIDS (Sudden Infant Death Syndrome) Alliance, Western New York**

**Affiliate** - 3580 Harlem Road, Suite 5, Buffalo, NY 14215

Contact: Mary Ellen Flynn (716) 837-7438

#### **Monroe County**

**SIDS (Sudden Infant Death Syndrome) Alliance, Greater Rochester**

**Affiliate** - 147 Edgeview Lane, P.O. Box 17424, Rochester, NY 14618

Contact: Lynn Bohlman DeWilde (716) 223-1888

**SIDS - Sudden Infant Death Syndrome Support Group** - Helen Wood Hall, 255 Crittenden Boulevard, Rochester, NY 14617

Contact: SIDS Alliance (716) 436-4070

#### **Onondaga County**

**SIDS Foundation - Upstate New York Chapter**

Contact: Nessa Vercillo-DeGirolamo (315) 474-1656

#### **Schenectady County**

**SIDS (Sudden Infant Death Syndrome) Alliance, Hudson-Mohawk**

**Affiliate** - 2431 Barton Avenue, Rotterdam, NY 12306

Contact: Frank LeGere (518) 355-5984

#### **Suffolk County**

**SIDS (Sudden Infant Death Syndrome) Alliance, Long Island Affiliate**

P.O. Box 342, Deer Park, NY 11729

Contact: William Lawrence (516) 321-SIDS

**Westchester County**

**Bereaved Parents Outreach of Holy Innocents - Holy Innocents Church,**  
Pleasantville, NY 10570

**Contact:** Anne Byrnes (914) 769-8753

**Compassionate Friends - North Salem Center, Route 116 and 121,**  
North Salem, NY 10560

**Contact:** Judy Mongiello (914) 669-5087

**Perinatal Bereavement Support Group - White Plains Hospital Center, Davis**  
Avenue, White Plains, NY 10601

**Contact:** Donna Kleinberger (914) 681-1047 or Judy Valentine (914) 681-1095

## KIDNEY

### Nassau County

**Parent Support Group for Children with Chronic Renal Disease - 4 Levitt**  
Building, North Shore University Hospital, 300 Community Drive, Manhasset, NY 11030  
Contact: Dr. Manju Chandre (516) 562-4383

### Monroe County

**National Kidney Foundation of Upstate New York, Inc.**  
Contact: Phyllis Lasky, Executive Director (800) 724-9421

## **LIMB DISORDER**

### **New York City**

#### **Manhattan**

**ASPIRE** - Memorial Sloan-Kettering Cancer Center, Nursing Department, 1275 York Avenue, New York, NY 10021

Contact: Paddy Rossbach (212) 639-6713

#### **Erie County**

**CHERUB, Inc.** - Robert Warner Rehabilitation Center, 936 Delaware Avenue, Buffalo, NY 14209

Contact: Carl Richenberg (716) 762-9997 or Thomas Houser (716) 692-5157

## LIVER DISEASE

### Nassau County

American Liver Foundation, Long Island Chapter - 101 Shinbone Lane,  
Commack, NY 11725  
Contact: Rhoda Blicht (516) 543-2700



## **LUPUS**

### **New York City**

#### **Bronx**

**Lupus Foundation of America, Bronx Chapter - Montefiore Hospital, 111 East 210th Street, Bronx, NY 10467**

**Contact: Rosa Gillespie (718) 822-6542**

#### **Brooklyn**

**Lupus Foundation of America, Brooklyn/Long Island/Queens Chapter - 1602 Bellmore Avenue, North Bellmore, NY 11710**

**Contact: JoAnn Quinn (516) 783-3370**

#### **Manhattan**

**Lupus - Hospital for Special Surgery, 535 East 70th Street, New York, NY 10021**

**Contact: Roberta Horton, CSW (212) 606-1271**

**SLE (Systemic Lupus Erythematosus) Foundation - 149 Madison Avenue, Room 608, New York, NY 10016**

**Contact: Enid Engelhard, CSW (212) 685-4118**

#### **Queens**

**Lupus Foundation of America, Long Island/Queens Chapter - 1602 Bellmore Avenue, North Bellmore, NY 11710**

**Contact: JoAnn Quinn (516) 783-3370**

### **Albany County**

**Lupus Foundation of America, Northeastern New York Support Group  
McKnowville Methodist Church, Route 20, Westmere, NY 12203**

**Contact: Gale Hack (518) 465-3603**

### **Broome County**

**Lupus Support Group**

**Contact: Judith Jones (607) 772-6522**

### **Nassau County**

**Lupus Foundation of America, Long Island/Queens Chapter - 1602 Bellmore Avenue, North Bellmore, NY 11710**

**Contact: JoAnn Quinn (516) 783-3370**

**Onondaga County**

**Lupus Foundation of America, Central New York Chapter - Maria Regina Center, Building B, 1118 Court Street, Syracuse, NY 13208**  
**Contact: Bernice Futerman (315) 472-6011**

**Orange County**

**Lupus Foundation of America, Rockland/Orange County Chapter - Horton Hospital, 60 Prospect Avenue, Middletown, NY 10940**  
**Contact: Martha MacRobbie (914) 354-0372**

**Rockland County**

**Lupus Foundation of America, Rockland/Orange County Chapter - Good Samaritan Hospital, Route 59, Suffern, NY 10901**  
**Contact: Martha MacRobbie (914) 354-0372**

**Suffolk County**

**Lupus Foundation of America, Long Island/Queens Chapter - 1602 Bellmore Avenue, North Bellmore, NY 11710**  
**Contact: JoAnn Quinn (516) 783-3370**

## LYME DISEASE

### Westchester County

**Northern Westchester Lyme Disease Support Group**

Contact: Jill (914) 621-1602

**Westchester Children's Lyme Disease Support Group**

Contact: Pat Walsh (914) 472-3496 or Barbara Goldklang (914) 769-6243

**Westchester Lyme Disease Support Group - 85 Court Street,  
White Plains, NY 10601**

Contact: Betty Gross (914) 591-7023

## MARFAN SYNDROME

### New York City

#### **Manhattan**

**Marfan Syndrome Support Group** - Hospital for Special Surgery, 535 East 70th Street, 2nd Floor Lecture Hall, New York, NY 10021

Contact: Julie Kurnitz (212) 244-4270

## MUSCULAR DYSTROPHY

### Nassau County

**Duchenne Muscular Dystrophy - Parents Support Group - Pediatric Endocrinology and Metabolism, North Shore University Hospital, 300 Community Drive, Manhasset, NY 11030**

**Contact: Harold Rosenthal (516) 562-4635**

**Muscular Dystrophy - Child Development Center/Nassau County Medical Center, 2201 Hempstead Turnpike, East Meadow, NY 11554**

**Contact: Joan Rottas or Dr. Steve Matinsky (516) 542-3941**

## NEONATAL - PERINATAL

### New York City

#### Manhattan

**Neonatal Parents Support** - Columbia Presbyterian Medical Center, BH12N, Room 1213, 620 W. 168th Street, New York, NY 10032

Contact: (212) 305-8500

#### Queens

**Parent Support Group for Neonatal Intensive Care Parents** - Schneider Children's Hospital, Room 337, New Hyde Park, NY 11042

Contact: Carol Adelman, ACSW (718) 470-3429



## NEUROFIBROMATOSIS

### New York City

#### Manhattan

**Mt. Sinai Hospital Neurofibromatosis Center** - Mt. Sinai Medical Center, One Gustave Levy Plaza - Box 1137, New York, NY 10029

Contact: Jane Halperin (212) 722-1784

#### Nassau County

**Neurofibromatosis Support Group** - North Shore Community Hospital, Child Development Center, 444 Community Drive, Manhasset, NY 11030

Contact: Ann Shields, CSW (516) 562-8436

#### Putnam County

**Neurofibromatosis - Telephone Support**

Contact: Susan Novak (914) 528-9121

## NEUROLOGICAL IMPAIRMENT

### New York City

#### Queens

**ANIBIC (Association for Neurologically Impaired Brain Injured Children)**

Contact: Michael Markais (718) 423-9550

### Broome County

**Disabled Adolescents Support Group - Handicapped Children's Association, 18  
Broad Street, Johnson City, NY 13790**

Contact: Joanne Novicky (607) 798-7117

### Erie County

**Rett Syndrome Support Group - 4163 South Park Avenue, Blasdell, NY 14219**

Contact: Kathy Dunham (716) 827-9185

### Onondaga County

**International Rett Syndrome Association - 111 Schuler Street, Syracuse, NY  
13203**

Contact: Joe and Ro Vargo (315) 422-7796

## PHYSICAL DISABILITIES

### New York City

#### **Brooklyn**

**Brooklyn Parent Advocacy Network** - St. Bartholomew's Church, 1227 Pacific Street, Brooklyn, NY 11216

Contact: Janet Holmes (718) 453-7171

#### **Manhattan**

**Manhattan Mothers and Others** - 160 East 65th Street, New York, NY 10021

Contact: Susan W. Williams (212) 570-6860

### Broome County

**Parent Support Group** - High Risk Births Clinic, 305 Main Street, Binghamton, NY 13905

Contact: Madelyn Wolf or Anne Rutledge (607) 729-1295

**Rehabilitation Services, Inc.** - 33 Mitchell Avenue, Binghamton, NY 13902

Contact: Denise Munson (607) 722-5308

**Southern Tier Independence Center** - 107 Chenango Street, Binghamton, NY 13901

Contact: Lori Rossen (607) 724-2111

### Cayuga County

**Options for Independence** - 75 Genesee Street, Auburn, NY 13021

Contact: Direct Services Advocate (315) 255-3447

### Franklin County

**Parents of Special Needs Children in Franklin County** - Meeting rotates among parents' homes.

Contact: Kathryn Brethour (518) 483-3198

### Herkimer County

**Parents of Children with Special Needs** - Herkimer County Hospice Office, 267 North Main Street, Herkimer, NY 13350

Contact: Laura Miller (315) 894-9447

### **Nassau County**

**Adolescents with Physical Disabilities** - North Shore University Hospital, Child Development Center, 444 Community Drive, Manhasset, NY 11030

**Contact:** Donna Donateli, MSW (516) 562-4637

**Support Group for School Age Children with Physical Disabilities** - North Shore University Hospital, Child Development Center, 444 Community Drive, Manhasset, NY 11030

**Contact:** Pamela Bongiorno, RN or Donna Donateli, MSW (516) 562-4637

### **Rockland County**

**Physically Handicapped Children's Program - Parents Resource Support Group** - Rockland County Department of Health, Sanatorium Road, Building D, Pomona, NY 10970

**Contact:** Esther Spiegel (914) 364-2622

### **Schuyler County**

**Schuyler Family Support Advisory Group** - Schuyler ARC, 203-205 12th Street, Watkins Glen, NY 14891

**Contact:** Connie Callanan (607) 535-6934

### **Suffolk County**

**Special Moms of Special Children** - Saint Anthony's Church, 614 Route 25A, Rocky Point, Long Island, NY 11778

**Contact:** Monica Harrison (516) 821-2174

### **Westchester County**

**The Family Resource Center** - Westchester Institute for Human Development, Cedarwood Hall/Westchester County Medical Center, Room C121, Valhalla, NY 10595

**Contact:** Barbara, Levitz, Elizabeth Diaz or Linda Caruso (914) 285-1343

**SPEAC (Services to Parents of Westchester Asian Children)**

**Contact:** Hisako Cunningham (914) 285-8174 or Y. Hayama (914) 939-1042

## **PKU**

### **Erie County**

**Western New York PKU Association of Families, Friends and Children  
with PKU and Other Metabolic Disorders, Inc. - Robert Warner Rehabilitation  
Center, 936 Delaware Avenue, Buffalo, NY 14209  
Contact: Barbara A. Rowe (716) 838-3452**

### **Nassau County**

**Parents of PKU  
Contact: Sue Arcario (516) 462-6878**

### **Suffolk County**

**Parents of PKU  
Contact: Sue Arcario (516) 462-6878**

## **PRADER-WILLI SYNDROME**

### **Erie County**

**Parent Support Group for Prader-Willi Syndrome**

**Contact:** Gloria Hanna (716) 627-9322

### **Monroe County**

**Prader-Willi Syndrome Parent Support Group - 366 Oxford Street, Rochester, NY 14607**

**Contact:** Volena Howe (716) 271-5332 (8:00 a.m. to 8:00 p.m.); Beth Lynch (716) 265-0066 or Sue Gilmore (716) 271-8826

### **Westchester County**

**Prader-Willi Syndrome Family Support Group - Westchester County Medical Center, Cedarwood Hall, Valhalla, NY 10595**

**Contact:** Terry Cousins (914) 285-8190



## PREMATURE AND SERIOUSLY ILL INFANTS

### New York City

#### Manhattan

**Parents to Parents** - New York Hospital, 525 East 68th Street, New York, NY 10021

Contact: Ellen Marticorena (212) 746-4326

#### Suffolk County

**Little Angel Fund** - P.O. Box 510, Selden, NY 11784

Contact: Jenny Tranfaglia (516) 736-2512

## REYE SYNDROME

### Westchester County

**Reye Syndrome Chapter** - 215 Union Avenue, Peekskill, NY 10566

Contact: Cathy DeCrenza (914) 739-7617 (telephone support)

## SHORT STATURE

### New York City

#### Queens

**Little People of America** - 330-07 91st Street, Jackson Heights, NY 11372  
Contact: Mary Fava (718) 507-2961

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## **SICKLE CELL**

### **New York City**

#### **Bronx**

**Sickle Cell Organizations for Self-Help** - Columbia Presbyterian Medical Center,  
6555 Broadway, Bronx, NY 10471

Contact: Mary Dean (718) 601-4140 or Darlene Bowle (718) 932-5940

#### **Brooklyn**

**The Sickle Cell/Thalassemia Patients Network at Interfaith Medical Center**  
555 Prospect Place, Brooklyn, NY 11238

Contact: Donnette Carroll (718) 935-7888

#### **Manhattan**

**Parent Education and Support Group** - St. Luke's Roosevelt Comprehensive  
Sickle Cell Center, 411 West 114th Street, #2C, New York, NY 10025

Contact: Elise Rackmill, CSW (212) 523-3105

**Sickle Cell Foundation of Greater New York City** - 127 West 127th Street,  
Room 421, New York, NY 10027

Contact: Dick Campbell (212) 865-1500

### **Albany County**

**Sickle Cell Support Group**

Contact: Cheryl (518) 766-4060

### **Erie County**

**Sickle Cell Disease Parent Association, Inc.**

Contact: Laverne Ampadu (716) 648-1964 or (716) 837-2073

### **Nassau County**

**Sickle Cell Support Group** - Nassau County Medical Center, Department of Pediatric  
Hematology, 2201 Hempstead Turnpike, East Meadow, NY 11554

Contact: Barbara Shotter, RN (516) 542-5798

### **Onondaga County**

**Comprehensive Sickle Cell Center Parents Support Group** - Pediatric  
Hematology - 5C, University Hospital, 750 East Adams Street, Syracuse, NY 13210

Contact: Dr. Stephen Dubansky (315) 464-5294

## **SPINA BIFIDA**

### **Broome County**

**Spina Bifida Support Group** - High Risk Births Clinic, 305 Main Street,  
Binghamton, NY 13905

Contact: Madelyn Wolf or Carole Rosen (607) 729-1295

### **Monroe County**

**Spina Bifida Association of Greater Rochester** - Al Sigl Center, 1000 Elmwood  
Avenue, Rochester, NY 14620

Contact: Kimberlee S. Richar (716) 381-2746 or Donna M. Willome (716) 381-5471

### **Nassau County**

**Spina Bifida Parents Group** - Nassau County Medical Center/Child Development  
Division, 2201 Hempstead Turnpike, East Meadow, NY 11554

Contact: Joan Rottas (516) 542-3941

### **Schenectady County**

**Spina Bifida Association - Albany/Capital District Chapter** - 1002 Seminole  
Road, Scotia, NY 12302

Contact: Christine Darby (518) 399-4360

### **Suffolk County**

**Spina Bifida Organization**

Contact: (516) 821-2974

## **TECHNOLOGY DEPENDENT**

**Also see listings for: 1) Chronic Illness and 2) Physical Disabilities**

### **New York City**

#### **Manhattan**

##### **Oley Foundation**

**Contact: Joan Bishop (800) 776-OLEY**

### **Westchester County**

**Westchester Advocates for Medically Fragile and/or Technology Dependent  
Children and Their Families - Richmond Children's Center, 919 North Broadway,  
Yonkers, NY 10701**

**Contact: Carol Baron (914) 968-1900**



## TOURETTE SYNDROME

### Erie County

Tourette Syndrome Children's Support Group - Western New York Chapter  
20 Thomas Jefferson Lane, Snyder, NY 14226  
Contact: Susan Connors (716) 839-4430

### Onondaga County

Tourette Syndrome Support Group - BOCES, Liverpool, NY 13090  
Contact: Sandy Portaleos (315) 451-6435

## TRACHEA/ESOPHAGEAL

### New Jersey

**TEF/VATER Support Network** - 45 Weldon Road, Edison, NJ 08817

Contact: Tracy Toth (908) 819-7885

## VISION

### Niagara County

**Retinoblastoma Family Outreach - 1618 Cleveland Avenue, Niagara Falls, NY  
14305**

**Contact: Deborah Battaglia (716) 284-6569**

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## APPENDIX I

### RESOURCE DIRECTORY EVALUATION FORM

1. Please check one:

\_\_\_\_\_ I am a parent of a child with special health needs.

\_\_\_\_\_ I provide services to children with special health needs.

2. Please check the ways you have used the directory:

\_\_\_\_\_ I called a network contact person for information about the network.

\_\_\_\_\_ I found one or more families I can talk to about my child's illness and connected with them.

\_\_\_\_\_ I joined one of the support networks listed in the directory.

\_\_\_\_\_ I contacted some of the resources listed in the directory.

\_\_\_\_\_ I referred a parent to one of the networks.

\_\_\_\_\_ I facilitate a network and called another network to exchange information.

3. Please list other kinds of information that would be useful in the directory.

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4. Please list suggestions you have for improving this directory.

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5. Please provide a list of other people who could benefit from receiving this directory.

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6. Please indicate any general reactions to this directory that you would like to share.

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7. If you are a parent, and used the directory to contact another parent, was the contact helpful? ☐ Yes ☐ No

Please explain.

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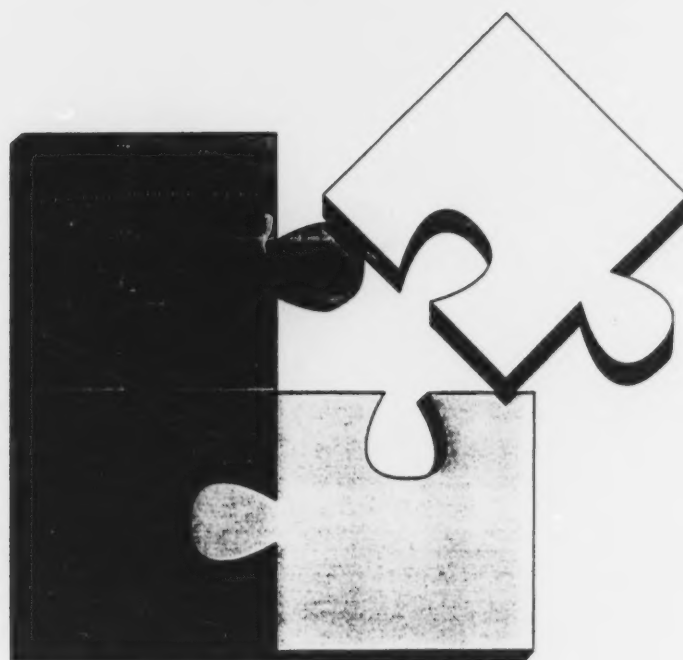
Thank you for completing this form. Please return it to:

Mary Huber  
NYS Department of Health  
Corning Tower, Room 208  
Empire State Plaza  
Albany, NY 12237

(518) 474-6781

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**Partners in Health:  
Self-Help Groups for Families  
of Children with  
Special Health Needs**



New York State Department of Health  
Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower

The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH

Lloyd F. Novick, M.D., M.P.H.

Director

Diana Jones Ritter  
Executive Deputy Director

March 24, 1994

Dear Colleague:

Enclosed is a copy of the manual developed for the project,  
*Partners in Health: Self-Help Mutual Support for Culturally Diverse  
Children with Special Health Needs and Their Families.*

The audience is leaders of community-based organizations (CBOs) who have the interest and resources to assist families of children with special health needs by establishing a parent support group, or responding in other creative ways. The manual is particularly geared to the leaders and natural helpers within culturally diverse communities, but has general applicability.

Major content areas include:

- ☐ A brief description of children with special health needs;
- ☐ Suggestions for initiating a parent support group;
- ☐ Suggestions for obtaining help for families from community based organizations that work with culturally diverse families;
- ☐ Materials for public awareness; and
- ☐ Statewide resources.

Examples of the way the manual can be used include the following:

- ☐ Families who want to start a network present the manual to a community based organization such as a church or Head Start program in order to lend credibility to the effort and to supply "how-to" information.

- ☐ Families whose children have special health care needs bring the manual to their schools as a way of validating the importance of family networks and to elicit the schools' support in advertising the parent network.
- ☐ Public programs that work with families who have children with special health care needs distribute the manual as part of their public awareness efforts to alert the community to the needs of families.

Only ten pages long, the manual is designed simply so it can be photocopied for mass production at a low cost. Although there are references that are unique to New York State, these references can be changed, or other references added, if the user has access to a Macintosh computer and PageMaker, a program for desktop publishing. Mail a blank Macintosh disk to: Mary Huber, NYS Department of Health, Corning Tower, Room 208, Empire State Plaza, Albany, NY 12237 (518) 474-6781. You will receive the document and then will be able to make any changes you wish. There is no charge for this service.

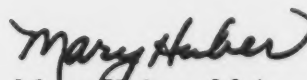
The document is also available in Spanish.

To request a copy of the manual, or additional information, contact Mary Huber at the above address.

Sincerely,

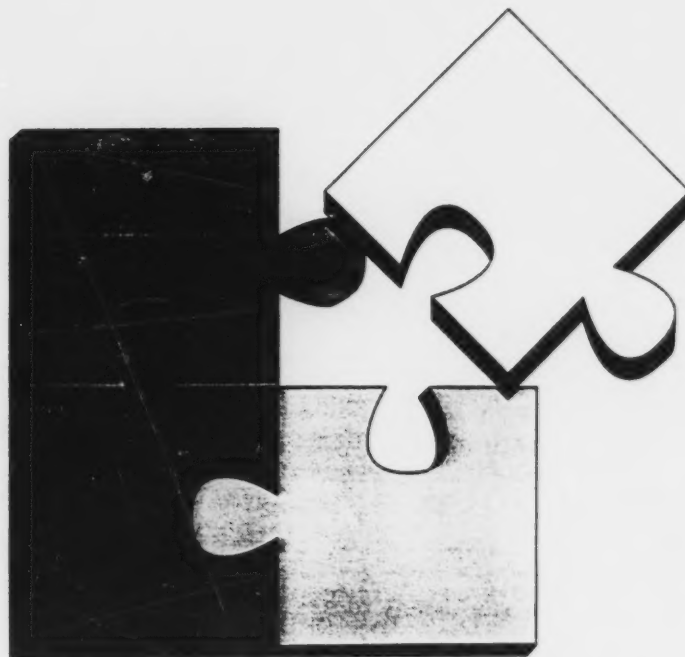


Christopher A. Kus, M.D.  
Director  
Bureau of Child and  
Adolescent Health



Mary Huber, M.A.  
Director  
Family-Professional  
Training Institute

**Socias para la Salud: Grupos  
de autoayuda para familias  
con niños que necesitan  
atención médica especial**



New York State Department of Health

Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Coming Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

Paula Wilson  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Lloyd F. Novick, M.D., M.P.H.  
Director  
Diana Jones Ritter  
Executive Deputy Director

6 de abril de 1994

Estimado colega:

Con la presente le remito un ejemplar del manual que hemos elaborado para el proyecto *Socios para la Salud: Grupos de autoayuda para familias de procedencias culturales diversas con niños que necesitan atención médica especial*.

El destinatario son los líderes de organizaciones con base en la comunidad (CBO, por su sigla en inglés) que tienen el deseo y los recursos necesarios para ayudar a las familias de niños que necesitan atención médica especial por medio del establecimiento de grupos de apoyo formados por padres de familia o a través de otras vías igualmente creativas. El manual está dirigido sobre todo a los líderes y a los colaboradores naturales dentro de comunidades culturalmente diversas, pero puede ser también de aplicación general.

Los siguientes son algunos de los temas tratados:

- ☐ Una breve descripción de los niños que necesitan atención médica especial,
- ☐ sugerencias para iniciar un grupo de apoyo formado por padres de familia,
- ☐ sugerencias para que las familias puedan obtener ayuda de organizaciones con base en la comunidad que trabajan con familias de procedencias culturales diversas,
- ☐ materiales para informar a la opinión pública, y
- ☐ recursos a nivel estatal.

Los siguientes son algunos de los muchos ejemplos de cómo puede ser usado este manual:

- ☐ Las familias que quieren crear una red comunitaria presentan el manual a una organización con base en la comunidad, tal como una iglesia o un programa *Head Start*, a fin de dar credibilidad a su esfuerzo y obtener información sobre cómo llevarlo a cabo.
- ☐ Las familias con niños que necesitan atención médica especial llevan el manual a sus escuelas respectivas. Este es un modo tanto de validar la importancia de las redes familiares como de obtener el apoyo de las escuelas para dar publicidad a las actividades de dichas redes.



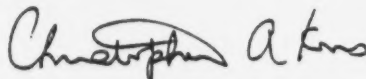
- ☐ Los programas públicos que trabajan con familias que tienen niños que necesitan atención médica especial distribuyen el manual como parte de sus esfuerzos por hacer consciente a la opinión pública a fin de informar a la comunidad sobre las necesidades de las familias.

El manual sólo tiene diez páginas de longitud y ha sido diseñado de manera sencilla para que pueda ser fotocopiado a bajo costo. Aunque se encontrarán en él referencias específicas al Estado de Nueva York, estas referencias pueden cambiarse, o bien añadirse referencias nuevas, con tal de que el usuario tenga acceso a una computadora y PageMaker (programa de edición de textos) Macintosh. Envíe por correo un disco Macintosh en blanco a: Mary Huber, NYS Department of Health, Corning Tower, Room 208, Empire State Plaza, Albany, NY 12237 (518) 474-6781. Se le enviará el documento y usted podrá realizar en el mismo todos los cambios que desee. Este servicio se proporciona de manera gratuita.

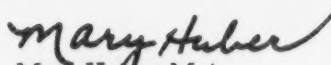
El documento se le puede proporcionar también en inglés.

Para obtener una copia del manual o información adicional, póngase en contacto con Mary Huber en la dirección arriba mencionada.

Atentamente,



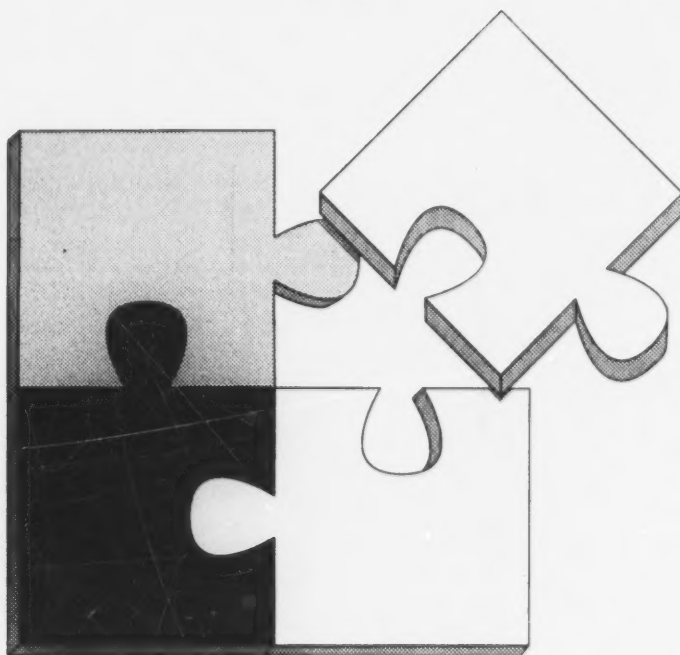
Christopher A. Kus, M.D.  
Director  
Oficina de Salud del  
Niño y del Adolescente



Mary Huber, M.A.  
Directora  
Instituto de Formación  
Profesional Familiar

# **Socias para la Salud**

***Grupos de autoayuda para familias con niños  
que necesitan atención médica especial***



**Departamento de Salud del Estado de Nueva York**

**L**a presente guía está dirigida a las personas que desean ayudar a las familias con niños que sufren de enfermedades crónicas o enfermedades que causan impedimentos físicos. Uno de sus objetivos principales es ayudar a esas familias a ponerse en contacto con grupos de apoyo y proporcionarles información sobre una serie de servicios que hay en su comunidad y que quizás no conocen.

Aproximadamente un 10% o un 15% de la población infantil de los Estados Unidos sufre de enfermedades crónicas o de enfermedades que causan impedimentos físicos. Dos de cada diez de esos niños padecen de trastornos de salud graves y prolongados. Esta cifra suele ser más elevada aún entre las familias que no tienen acceso a una buena atención médica. Generalmente, se trata de familias de bajos ingresos, familias que viven en zonas rurales aisladas y familias que pertenecen a diversos grupos étnicos, como los latinos, afroamericanos, indígenas americanos y asiáticos.

**Socios para la Salud** es un proyecto del Departamento de Salud del Estado de Nueva York que tiene por objeto ayudar a las familias con hijos que necesitan atención médica especial. El principal objetivo de este proyecto lo constituyen los niños y los adolescentes menores de 21 años con impedimentos físicos o enfermedades crónicas que les impiden crecer y desarrollarse. Entre esas enfermedades e impedimentos físicos están el asma, la parálisis cerebral, la fibrosis quística, la diabetes, la epilepsia, los trastornos genéticos, las enfermedades del corazón y la leucemia.

La finalidad de **Socios para la Salud** es informar a las familias de esos niños y jóvenes sobre la existencia de los grupos de apoyo y agencias de

servicios que hay en sus respectivas comunidades para que puedan relacionarse, intercambiar informaciones y compartir experiencias con personas que están en una situación similar.

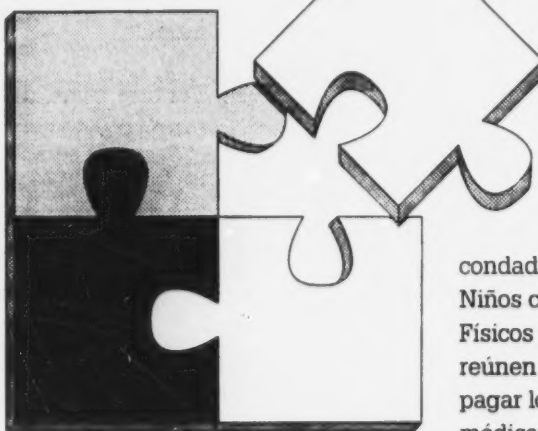
Los grupos de autoayuda de este tipo no surgen "como por encanto" en una comunidad. Alguien debe tomar la iniciativa y asumir la responsabilidad de organizar y coordinar los esfuerzos del grupo. Usted, como líder de su comunidad, es la persona indicada para desempeñar el papel de catalizador. Al crear una red de información en su comunidad, usted contribuirá a estrechar los lazos de amistad entre las familias de los niños que necesitan atención médica especial y a fortalecer sus vínculos tanto con las personas que pueden ayudar a atender esas necesidades como con la comunidad en general.

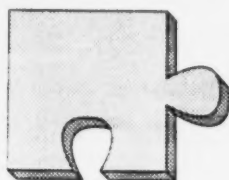
Para realizar esta labor, usted contará con la colaboración del Programa para Niños con Impedimentos

Físicos (PHCP, por su sigla en inglés) y del Programa de Intervención Oportuna del departamento de salud de su

condado. El Programa para Niños con Impedimentos Físicos ayuda a las familias que reúnen ciertos requisitos a pagar los gastos de la atención médica de los niños que sufren

de graves trastornos de salud a largo plazo. El Programa de Intervención Oportuna ofrece servicios gratuitos que pueden contribuir al crecimiento y desarrollo de los niños y también ayuda a las familias a conseguir la mejor atención médica posible para sus hijos. En todos los condados del Estado de Nueva York hay Programas para Niños con Impedimentos Físicos y Programas de Intervención Oportuna.





## El primer paso

Lo primero que usted deberá hacer es comprobar si dentro de

su comunidad se necesita un grupo de este tipo y buscar la manera más apropiada para atender las necesidades existentes.

Puede empezar hablando con algún miembro de la comunidad que tienen un hijo que necesita atención médica especial. Esa persona puede ayudarle a encontrar a otras familias que están en una situación similar. Haga una lista de esas familias y comuníquese con ellas para preguntarles si estarían interesadas en participar en un grupo de apoyo, o si conocen a otras familias cuyos hijos necesitan atención médica especial. De esa manera, comprobará si es necesario formar un grupo de autoayuda en su comunidad.

## Metas y objetivos

Una vez que encuentre a familias interesadas en participar en un grupo de autoayuda, organice una pequeña reunión para fijar las metas y los objetivos. ¿Qué esperan las familias de un grupo de autoayuda vinculado al programa **Socios para la Salud**? ¿Qué objetivos se deben alcanzar a corto y largo plazo? Las respuestas a estas preguntas servirán de base para fijar las metas y los objetivos del grupo.

Al fijar las metas y los objetivos no debe perder de vista la realidad. No debe buscar objetivos que estén fuera de las posibilidades del grupo porque si no se los consigue, usted y los miembros del grupo pueden desmoralizarse.



## Para encontrar a otros miembros

A medida que la lista de familias con hijos que necesitan atención médica especial vaya creciendo, usted deberá buscar a familias aptas para "reclutar" a otros miembros, eligiendo a dos o tres familias que se entusiasman a la idea de formar un grupo de autoayuda y preguntándoles si pueden traer a otras personas interesadas a la primera reunión.

Al hablar con posibles miembros, los "reclutadores" deben recalcar el hecho de que en el grupo se comparten las experiencias, se intercambia información y se presta ayuda mutua. Además, deben explicar que se trata de una manera informal de buscar la mejor forma de hacer frente a los problemas que se presentan de vez en cuando.

Por otra parte, usted debe explicar que el grupo puede ayudar a sus miembros a:

- introducir cambios positivos en su vida, haciendo todo lo que esté a su alcance;
- sentirse menos abrumados por los problemas, y
- abogar por los derechos de sus hijos y de otros niños. Al hacer esto, tenga presente que la clave para reclutar a otros miembros es el entusiasmo. Usted deberá despertar el entusiasmo de las personas y elegir a las más entusiastas para que ayuden a reclutar a nuevos miembros.

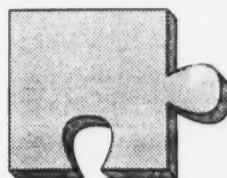
## La primera reunión



Si bien el hecho de ser miembro de un grupo de autoayuda del programa **Socios para la Salud** no representa gastos para sus miembros, las personas tienen que "aportar" algo — por ejemplo, tiempo o trabajo —, inclusive antes de incorporarse al grupo. Por lo tanto, al organizar la primera reunión usted debe:

1. Elegir un lugar accesible.
2. Elegir una hora conveniente.
3. Elegir a una familia conocida en la comunidad para que hable sobre el cuidado de un niño que necesita atención médica especial.
4. Preparar material para la reunión:
  - Metas y objetivos del grupo y
  - folletos o volantes de organizaciones locales que prestan servicios a las personas con impedimentos físicos.
5. Distribuir volantes para anunciar que se llevará cabo una reunión, indicando fecha, hora y lugar. Poner avisos en los tableros de información de los mercados y las lavanderías o en otros lugares de mayor circulación. Colocar anuncios en la columna de servicios de la comunidad del periódico local.
6. Preparar un programa que contenga, por ejemplo:
  - Palabras de salutación e introducción.
  - Antecedentes. Explicación de los motivos, métodos, metas y objetivos que el grupo se ha fijado.
  - Charlas de persona(s) invitada(s) para hablar sobre los beneficios de los grupos de autoayuda.

- Listas de firmas. Los asistentes deberán anotar su nombre, su dirección y número de teléfono. Si puede, saque fotocopias de esa lista y repártalas entre los asistentes al finalizar la reunión. De esa forma, los asistentes podrán mantenerse en contacto si lo desean.
- Reclutamiento. Diga a los asistentes que recluten a otras familias con hijos que necesitan atención médica especial.
- Fijar la fecha de la siguiente reunión.



## Participación de la comunidad

Además de los grupos de autoayuda, hay otras maneras de ayudar a las familias con hijos que necesitan atención médica especial. Una de ellas es recurrir a las organizaciones locales, por ejemplo, al Club Kiwanis, Club Rotario, YMCA/YWCA, grupos de iglesias y hospitales para pedirles su colaboración. También se puede acudir a organizaciones de profesionales como la Asociación de Enfermeras Afroamericanas, la Asociación de Enfermeras Hispanas, las fraternidades que se dedican a ayudar a la sociedad y las organizaciones que ayudan a los adolescentes.

Hay muchas maneras de obtener la colaboración de las organizaciones y de informar a la comunidad sobre el programa **Socios para la Salud**. Por ejemplo, se puede:

- Invitar a expertos de la localidad para que den charlas sobre los niños que necesitan atención médica especial y sobre los servicios que ofrece la comunidad.



- Distribuir a los miembros el folleto del programa **Socios para la Salud** durante los acontecimientos especiales.
- Publicar en el boletín de la organización artículos sobre el programa **Socios para la Salud** o sobre alguna familia cuyo hijo que necesita atención médica especial.
- Pedir a los miembros de la organización que busquen a otras familias con hijos que necesitan atención médica especial y les recomienden que se dirijan al programa **Socios para la Salud** de su localidad.
- Prestar su casa para realizar una reunión, cuidar a un niño que necesita cuidado especial o invitar a personalidades destacadas para que hablen en la reunión del grupo de autoayuda.
- Buscar a padres de familia con experiencia para que se hagan amigos o consejeros de las familias con hijos que necesitan atención médica especial.
- Organizar actividades recreativas para los niños que necesitan atención médica especial y/o para sus familias.
- Hacer una colecta de fondos para pagar los gastos de las reuniones del grupo o en beneficio de alguna familia que tenga un hijo que necesita atención médica especial.
- Ofrecer tiempo, material informativo o algún medio de transporte para ayudar a los padres con hijos que necesitan atención médica especial.



## Para transmitir el mensaje del grupo

Los medios más rápidos y eficientes de transmitir el mensaje del grupo al mayor número de personas posible son la radio, la televisión y los periódicos diarios y semanales. Para ello, es necesario tener alguna noticia que valga la pena publicar. De acuerdo con la definición de los medios de comunicación social, noticia es un acontecimiento que puede interesar a los lectores o espectadores. ¿Qué hace la gente? ¿Por qué lo hace? ¿De qué manera afectan o benefician sus acciones a otras personas?

Después de identificar todo aquello que vale la pena publicar acerca del grupo, se debe hacer una lista de todos los periódicos y estaciones de radio y televisión que cubren el ámbito de su proyecto. Además de nombres, direcciones y números de teléfono, se deben anotar los números de fax. En la lista, deben incluirse los nombres de los reporteros y redactores de noticias relacionadas con la salud, los redactores de artículos sobre diversos estilos de vida, directores de programas y servicios públicos y redactores de noticias.

Elija a una persona clave como portavoz del grupo. Esa persona tiene que estar dispuesta a trabajar con los medios de comunicación social, debe saber escuchar, ser espontánea, tener experiencia práctica en la materia y facilidad para aprender.

El/la portavoz deberá ponerse en contacto con las personas de la lista para presentar al grupo. Además, deberá averiguar los plazos y el tiempo que los medios de comunicación necesitan para publicar artículos, cronogramas, avisos de servicio público o



comunicados de prensa. Como la prensa tiene fechas fijas para cumplir su trabajo, su tiempo es limitado y valioso. Por lo tanto, se debe ser breve e ir directamente al grano.

Siempre que le sea posible, organice reuniones con los reporteros, redactores y directores de programas y servicios públicos para informarles sobre las necesidades de los niños que requieren atención médica especial, las necesidades de la comunidad y sobre la labor del grupo. Antes de acudir a una reunión, deberá escribir una carta con datos

sobre los niños que necesitan atención médica especial. Lea todas las noticias que pueda sobre dichos niños y procure conocer personalmente al reportero o reportera encargados de redactar este tipo de noticias (puede invitarle a la reunión del grupo).

Otra forma de transmitir el mensaje es acudir a la prensa oral y escrita o difundir avisos de servicio público. Además, puede llamar la atención de un reportero sobre el grupo con historias de interés humano sobre este tipo de niños.



## Difusión de noticias

Las noticias deben ser sencillas y breves, en tono de conversación. Los datos más importantes deben

mencionarse en el primer y segundo párrafos. Los párrafos deben ser breves, con dos o cuatro oraciones cada uno, e ir directamente al grano. No haga comentarios, mencione hechos, no opiniones. Escriba las noticias a máquina, en renglones de doble espacio en un papel con el membrete del grupo. No se olvide poner en el extremo superior de la derecha el nombre y apellido y el número de teléfono de la persona a la que debe dirigirse. Además, en la parte de arriba deberá escribir: PARA DIFUSION INMEDIATA o PARA DIFUSION EL (día/mes/año). Busque un título que capte la esencia de su aviso. Aunque no se utilice ese título como titular del aviso, informe al redactor sobre el contenido del mismo. Si el artículo ocupa más de una página, al final de la página escriba: (continúa). Con -30- se indica que el aviso ha terminado.

**Ejemplo de  
AVISOS PARA LA PRENSA:**

Si desea más información, llame a:  
(Su nombre y apellido)  
(Cargo que desempeña)  
(Número de teléfono)

### PARA DIFUSION INMEDIATA:

(Nombre de la comunidad) NUEVO MIEMBRO  
DE SOCIOS PARA LA SALUD

(Nombre de la ciudad/pueblo) (fecha) -  
En (ciudad/pueblo) hay (número de niños)  
niños que necesitan atención médica especial. Esos niños necesitan su ayuda. El (nombre del grupo) se reunirá el (fecha) para (objeto del acontecimiento/reunión).

Datos estadísticos sobre los niños que necesitan atención médica especial:

- Del 10% al 15% de los niños tienen enfermedades crónicas o enfermedades que causan impedimentos físicos. De ellos, el 1% o el 2% sufre de trastornos de salud graves y prolongados, como el asma, la parálisis cerebral, la fibrosis quística, la diabetes, la epilepsia, trastornos genéticos, enfermedades del corazón y leucemia.

(continúa)

- Hay programas que pueden ayudar a las familias a cuidar a los niños que necesitan atención médica especial. **Socios para la Salud** ayuda las familias que tienen esta clase de hijos a vincularse entre sí para que compartan experiencias, intercambien información y se ayuden mutuamente.

Si usted conoce a una familia o persona que tiene un hijo que necesita atención médica especial, avíseles que hay una organización llamada **Socios para la Salud**.

Usted también puede ofrecer su ayuda voluntaria a las familias que tienen hijos con impedimentos físicos. Si desea más información, diríjase al (nombre del grupo), (dirección), llamando al (número de teléfono).

- 30 -



## Avisos de servicio público

Los avisos de servicio públicos son mensajes de 10, 20 ó 30 segundos de duración que las estaciones de radio y televisión transmiten durante los espacios de publicidad que no han sido vendidos o durante las pausas para identificar a la radioemisora o el canal de televisión. Los avisos de servicio público deben contener un solo punto básico y pedir a la audiencia que tomen alguna iniciativa. Las oraciones deben ser breves pero elocuentes para atraer la atención del radioescucha o televidente. El estilo debe reflejar el modo de hablar del autor, en tono claro e informal sin complicaciones. Varíe la longitud de las oraciones para que el ritmo sea agradable. Escoja las palabras más apropiadas y precisas para hacer descripciones. Lea siempre el aviso en voz alta para comprobar cuánto tiempo tarda a una velocidad normal. Si el mensaje es para la televisión, añada un dispositivo de 35 mm con el nombre y el número de teléfono de su grupo.

### Ejemplos de AVISOS PARA RADIO O TELEVISION:

#### 30 segundos:

¿Está usted solo con un niño que tiene enfermedades crónicas o impedimentos físicos? ¿No sabe adónde acudir en busca de ayuda? El (nombre del grupo) puede ayudarle a ponerse en contacto con otras familias que están en su situación. Si desea más información, llame al (número de teléfono).

#### 30 segundos:

¿No puede encontrar el servicio especial que necesita su hijo? **Socios para la Salud** es un grupo de padres y familiares de (nombre de la comunidad) que comparten experiencias, intercambian información y se ayudan mutuamente. Para pedir más información sobre el programa **Socios para la Salud** de (nombre de la comunidad), llame al (nombre del grupo) al (número de teléfono).

#### 20 segundos:

¿Tiene usted un hijo con impedimentos físicos o enfermedades crónicas? El (nombre del grupo) le puede enseñar a ayudarse a sí mismo y a otras personas. Si desea más información, llame al (número de teléfono).

#### 20 segundos:

**Socios para la Salud** une a las familias. Si usted o un amigo suyo tiene un hijo que necesita atención médica especial, **Socios para la Salud** le puede ayudar. Llame al (nombre del grupo) al (número de teléfono) para pedir más información.

#### 20 segundos:

¿Sabía usted que un 10% o un 15% de los niños sufre de impedimentos físicos o enfermedades crónicas? Si su hijo está entre ellos, (nombre del grupo) le puede ayudar. Llame al (número de teléfono).



## Hojas informativas

Si su comunidad publica hojas informativas semanales, sería aconsejable que anuncie

ahí sus proyectos. El anuncio no debe ser muy largo, bastan unas cuatro o cinco oraciones para informar al público sobre el grupo y los objetivos que se ha fijado y para avisar cuándo y dónde se llevará a cabo la reunión.

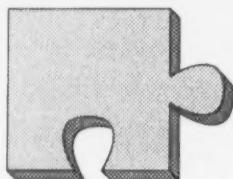
### Ejemplos de AVISOS PARA HOJAS INFORMATIVAS:

#### Anuncio No. 1:

¿Tiene un hijo/a que necesita atención médica especial? ¿Necesita ayuda y no sabe adónde dirigirse? Precisamente en (nombre de la comunidad) hay un programa de ayuda para las familias con hijos que tienen impedimentos físicos o enfermedades crónicas. **Socios para la Salud** vincula a las familias con hijos que necesitan atención médica especial para que compartan sus experiencias, intercambien información y se ayuden mutuamente. El (día), a las (hora) en (lugar), se realizará una reunión a la que puede asistir todas las personas interesadas. Si desea más información, llame al (número de teléfono).

#### Anuncio No. 2:

Un 10% o 15% de los niños tienen impedimentos físicos o sufren de enfermedades crónicas. Un 1% o 2% de esos niños padecen de trastornos graves de largo plazo como el asma, la parálisis cerebral, la fibrosis quística, la epilepsia, las enfermedades del corazón o la leucemia. **Socios para la Salud** patrocina un programa de ayuda a las familias que tienen hijos que necesitan atención médica especial. **Socios para la Salud** colabora a esas familias a vincularse entre sí para compartir experiencias, intercambiar información y ayudarse mutuamente. El día (día de la semana) a las (hora) se realizará en (lugar) una reunión de familias interesadas en este programa. Si desea más información, llame al (número de teléfono).



## **Más información**

Si desea más información sobre los servicios para niños

que necesitan atención médica especial, diríjase al Programa de Niños con Impedimentos Físicos o al Programa de Intervención Oportuna del departamento de salud de su condado. Algunos condados también tienen centros de información sobre programas de autoayuda que pueden prestarle asistencia para que organice un grupo. Llame a la Oficina del Representante de Personas Incapacitadas al 1-800-622-4369 para pedir la dirección del centro de informaciones que le quede más próximo.

### **Numeros gratuitos con prefijo 800**

#### **La Década del Niño**

Teléfono: 1-800-345-5437

Horario: De lunes a viernes, de 8.30 a.m. a 5.00 p.m.

Información sobre los programas del Estado de Nueva York para niños y padres de familia (cuidado de niños, nutrición, vacunas, programas de orientación y apoyo para padres de familia, programas sobre el embarazo en las adolescentes, alcoholismo y drogadicción).

### **Línea directa para la donación de alimentos**

Teléfono: 1-800-462-3663

Horario: De lunes a viernes, de 8.00 a.m. a 4.30 p.m.

Referencias sobre los centros de distribución del excedente de alimentos de USDA y centros comunitarios de distribución de alimentos.

### **Información sobre cursos de autoafirmación y red de referencias**

Teléfono (también para personas con pérdida de la audición): 1-800-522-4369

Horario: De lunes a viernes, de 9.00 a.m. a 12.00 p.m. de 1.00 p.m. a 4.45 p.m.

Información sobre los servicios, la protección de las leyes y otros mecanismos de protección para personas con impedimentos físicos, sus familias y las personas que les prestan servicios.

### **Línea directa de la Campaña de Salud Infantil**

Teléfono: 1-800-522-5006

Horario: De lunes a domingo, los siete días de la semana, las 24 horas del día

Información sobre el programa WIC del Departamento de Salud del Estado de Nueva York, pruebas del embarazo, atención prenatal, vacunaciones y seguro de salud infantil gratuitos.

*Este manual ha sido elaborado en colaboración con los responsables del Proyecto # MCJ367034010 de la Oficina de Salud Materno/Infantil (Título V, Ley de Seguro Social), con la Administración de Servicios y Recursos para la Salud y con el Departamento de Salud y Servicios Humanos.*

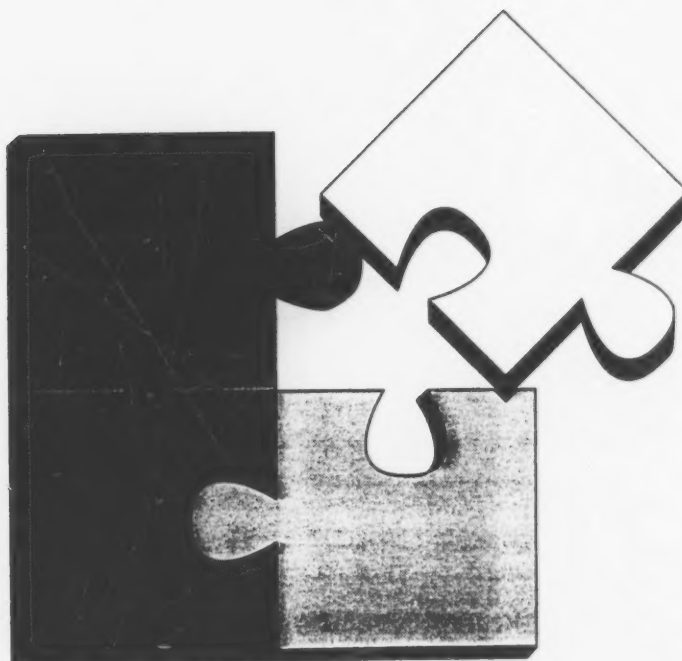


Estado de Nueva York  
Mario M. Cuomo, Gobernador

Departamento de Salud  
Mark R. Chassin, M.D., Comisionado



# **Parent Satisfaction Questionnaire**



New York State Department of Health  
Bureau of Child and Adolescent Health

## Partners in Health

Name of Interviewer \_\_\_\_\_

The clearinghouse receives funding to provide this service from the federal government. In order to evaluate the success or failure of our services, we need to find out if our service was useful to you and how to most benefit consumers like you. By spending a few minutes with me, you can help us figure out if we are doing our job.

The following questions concern the person with whom the self-help clearinghouse has had contact.

Write or circle the appropriate response.

Before we begin with questions about our services, I would like to ask a few questions about you and your child with special health needs.

What is your sex?                      1. Male                      2. Female

Are you Hispanic?              1. Yes                      2. No

If NO, then ask:

Are you:              1. White                      4. Black  
                         2. Native American              5. Other (Please  
                         3. Asian                      explain)\_\_\_\_\_

What is your relationship to the child who has special health needs?

1. Mother                      5. Friend of the Family  
2. Father                      6. Provider of Services  
3. Foster Parent              7. Other: Please Explain  
4. Grandparent              \_\_\_\_\_

Are you the primary caregiver of a child with special health needs?

1. Yes                      2. No

What is the child's diagnosis ? \_\_\_\_\_

What is the age of the child who has the special health need? \_\_\_\_\_

I am interested in knowing what happened as a result of your call to the clearinghouse. Please answer yes or no to the following questions:

When you called the clearinghouse, did you receive information on services that are available for you              Yes                      No

That were available for your child?              Yes                      No

Did you use any of the services you learned about?

Yes

No

Did your child use any services you learned about?

Yes

No

Which ones were they?

You

Your Child

Other Members  
of Family

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As a result of calling the clearinghouse, did you learn about the case management program sponsored by the \_\_\_\_\_ County Department of Health?

Yes

No

Did you join the case management program? Yes No

If the answer is NO, ask:

Could you tell me why you didn't join the case management program? \_\_\_\_\_

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As a result of calling the clearinghouse, did you receive information about self-help groups for families who have children with special health needs?

Yes

No

Did you call the support network contact person to find out about the group?

Yes

No

Did you join a support network? Yes No

If the answer is NO, ask:

Can you tell me why you didn't want to become a part of the parent network?

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If the answer is YES, ask:

Please tell me if any of the following things happened because you joined the group:

In the group, did you meet other people you could talk to about your child's illness? Yes No

Through these discussions, did you learn more about your child's illness? Yes No

Did you learn from other parents about practical things you can do to help yourself or your child? (Some examples of this are: easier ways to dress a child, administer medicine, finding playmates, and so forth.) Yes No

Did you learn from other parent about any services you didn't know about before?

(Some examples are:

Speech Therapy  
Remedial School Help  
Home Instruction  
Social Recreational Opportunities  
Special Diagnostic and Evaluation Services  
Transportation

Can you tell me which ones you learned about?

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Did you learn about any financial assistance you didn't know about before? (Check all that apply.)

Medicaid

State-Aid/Physically Handicapped Children's Program

Third Party Health Insurance (Blue Cross/other private insurance)

Health Maintenance Organization (HMO)

SSI (Supplemental Security Income)

SSA (Social Security Disability)

AFDC (Welfare, Social Services)

Food Stamps

WIC (Women, Infants and Children Program)

Home Relief/Public Assistance

Other (please specify)\_\_\_\_\_

As a result of joining the network, do you feel you have a place to turn to when you are in need that you didn't have before?

Yes

No

As a result of joining the group, did you make any new relationships?

Yes

No

Do the group members ever help each other out in practical ways, such as taking care of each other's children?

Yes

No

Have you referred any other parents to this support network ?

Yes

No

Through membership in the self-help group, have you helped another parent?

Yes

No

Please

explain. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

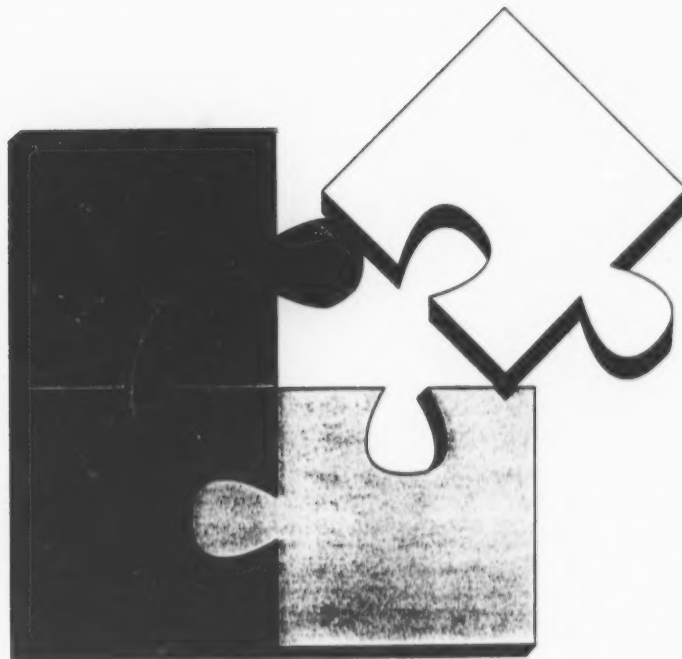


Do you have any general comments or suggestions about improving clearinghouse services? Yes ☐ No ☐

If there are comments, make note of them here.

[illegible]

# **Evaluation Questionnaire for Partners in Policy Making**



New York State Department of Health  
Bureau of Child and Adolescent Health



STATE OF NEW YORK  
DEPARTMENT OF HEALTH

Corning Tower

The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.  
Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

December 26, 1992

Dear Partners in Policy Making Participants:

Enclosed is a brief survey whose purpose is to identify the effect of your participation in Partners in Policy Making. This assessment will be very helpful in determining future program needs and will assist in developing proposals to obtain funds for additional parent training.

Please review the entire survey before you begin answering the questions. I would also appreciate it if you would return the survey as quickly as possible.

Thank you for your help. Best wishes to you and your families in 1993.

Sincerely,

Mary Huber, Director  
Partners in Health

Enclosure

## Partners In Policy Making Follow-up Survey

This survey is an effort to measure some outcomes of results of your participation in the Partners in Policy Making program. One way to evaluate the effectiveness of the Partners program is to collect information about how your participation in the program has helped you become a better advocate after graduation. In this effort, please answer the questions below.

1. Please evaluate your advocacy skills, for yourself or a family member with a disability, prior to the Partners program.

- ☐ a. Excellent
- ☐ b. Very Good
- ☐ c. Good
- ☐ d. Fair
- ☐ e. Poor

2. Have you been in contact with local, state, or national public officials since the Partners training? (Check all that apply.)

- ☐ a. Yes, national public officials
- ☐ b. Yes, state public officials
- ☐ c. Yes, local public officials
- ☐ d. No

3. If yes to Number 2, please indicate the type of contact, (letter, phone, or office visit) and estimate the number of contacts made. (Check all that apply.)

- ☐ a. Letters
- ☐ b. Phone calls
- ☐ c. Office visits

Estimated number

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4. What other opportunities have you had to advocate for yourself or other persons with disabilities? (Check all that apply.)

- ☐ a. Testified at a public hearing
- ☐ b. Service on a committee/commission

Estimated number

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5. What other opportunities have you had to advocate for yourself or a family member with disabilities within a school, work or health care setting? (Check all that apply.)

- ☐ a. School setting
- ☐ b. Work setting
- ☐ c. Health care setting

Estimated number

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7. Have you participated in any public education efforts about persons with disabilities since Partners in Policy Making?

- Estimated number

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- ☐ a. Yes  
☐ b. No

- [illegible]

10. As a result of your participation in Partners, have you:

- ☐ a. started a new parent support group.
- ☐ b. maintained supportive relationships with other parents you met at Partners.
- ☐ c. shared the information you learned at Partners with other parents of children with special needs.

11. If yes, to number 10, please provide specific examples here:

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12. Please outline any other benefits or outcomes you can attribute to your participation in the Partners program not mentioned above:

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Your Name: \_\_\_\_\_

How many sessions of Partners did you attend?

- ☐ one      ☐ two      ☐ three

Where were they located?

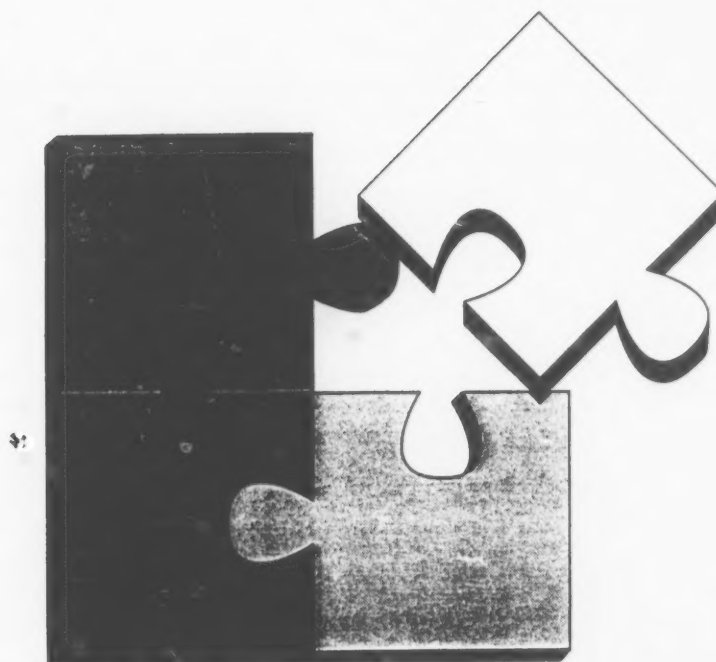
- ☐ Albany      ☐ Batavia      ☐ New York City

After you have completed this form, please return as soon as possible to:

**Mary Huber**  
**New York State Department of Health**  
**Bureau of Child and Adolescent Health**  
**208 Corning Tower Building**  
**Albany, NY 12237**  
**(518) 474-6781**



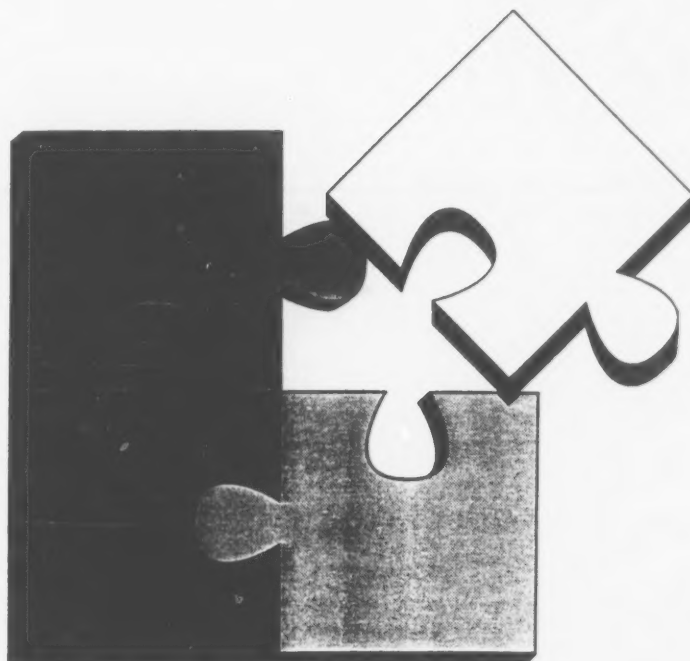
# **Report of Self-Help Clearinghouse Focus Group**



New York State Department of Health  
Bureau of Child and Adolescent Health

# **Report of the Self-Help Clearinghouse Focus Group**

**Conducted in Albany, NY  
September 17, 1993**



**New York State Department of Health**

**Participants:**

Mary Huber - Project Coordinator

Terri Seidel - Niagara County Clearinghouse

Miriam Montalvo - Long Island Clearinghouse

Isiaka Abayomi Bolarinwa - Schenectady County Clearinghouse

John Holcomb - Project Analyst

## **I. DID YOU DEVELOP A GOOD RELATIONSHIP WITH THE CASE MANAGEMENT PROGRAM?**

Terri:

Terri stated that Partners in Health had a good relationship with the case managers mainly because the staff at the Niagara County Clearinghouse knew the case managers prior to this project. The Clearinghouse and the case managers often shared resources and attended in-service training sponsored by each organization. In fact, one case manager attended a group leader training session Terri conducted at the Clearinghouse because the case manager wished to begin a parent support group. Terri gave them information and support.

In addition, the Case Management Program asked Terri to serve on a quarterly committee to examine the files of a small sample of cases. Terri's role consisted of examining the role the case manager played in serving that particular family. An open communication existed between the Clearinghouse and case managers of which one result was that the case managers often called the Clearinghouse requesting information on support groups for their clients. These calls were for families who had no connection to the Clearinghouse but did receive information on support groups from Partners in Health. Unfortunately, there is no way to determine if these parents joined a support group.

Bola:

Bola had a good relationship with the Case Management Program. He was able to provide them with resources and information for their Individualized Family Service Plan (IFSP). They also collaborated on a conference for chronically ill children. He noticed that when doing community outreach, they were better received when they made a joint presentation. Confidentiality requirements made it difficult to learn if the families followed through on attending a support group. He felt the greatest contribution was the inclusion of support group information in the IFSP conference and the current policy of including Clearinghouse service information in the packets sent to families by the case managers. Overall, Bola felt they had a good and productive relationship, but it could have been even better if they could have collaborated on more projects together.

Miriam:

Miriam found when she began working at the Clearinghouse that a strained relationship existed between the Clearinghouse and the Case Management Program. Since that time, however, a great relationship has evolved. She has consulted the case managers on opportunities to outreach in Nassau County. The case managers have asked Miriam to translate for them in certain situations. A case manager in Suffolk County also asked Miriam to a special prayer group in the Hispanic community for families with special needs. Although these families did not know it, they were acting as a self-help/mutual support group. After Miriam's visit, the Clearinghouse received calls from these participants and some became clients.

It is also interesting to note that Suffolk County has recently hired two Spanish speaking case managers; this may be a result of the influence of Partners in Health.

When asked if they had any questions for the case managers, the participants wanted to know if speaking Spanish was a major factor in the hiring of the new case managers. They also wondered if bilingual education programs could be incorporated into the case manager's training.

## **II. WHAT STEPS DID YOUR ORGANIZATION TAKE TO DEVELOP CULTURALLY COMPETENT SELF-HELP CLEARINGHOUSES?**

Terri:

Niagara County has sponsored cultural awareness seminars given by human service workers. Niagara Community College has also sponsored a series of cultural awareness seminars. The Clearinghouse staff attended some facets of both these seminars. In fact, all eleven employees of the agency have attended at least one cultural awareness session.

The agency has also started a program called "Lunch Connections" where agency staff meet during lunch and perform exercises with the goal of learning more about the presenter's culture and history.

The director also plans to introduce programs to make the Board of Directors of the agency more culturally aware. Terri feels Partners in Health was very instrumental in making this occur. Without Partners in Health, cultural awareness would not be an issue at all. Terri herself intervened to make sure the staff registered and actually attended the seminars previously mentioned.

The Niagara County Clearinghouse also hired Liz, a Native American. Upon her hiring, Terri noticed a feeling by some of the more experienced staff of bewilderment as to how this would be beneficial. This may have been a reason the executive director was so adamant about everyone attending the cultural awareness seminars.

Bola:

Bola's hiring is evidence of increasing cultural awareness. He is a bilingual African American. More African Americans, as well as an Asian, now sit on the Board of Directors. He believes Partners in Health enlightened the executive director to the issue of cultural competency.

Bola was also able to translate Clearinghouse brochures and flyers into Spanish, and although the Clearinghouse has yet to have a Spanish speaking individual answering the information line, he feels they have at least initiated outreach to this important part of the culturally diverse community.

Miriam:

Miriam believes the cultural competency of the Clearinghouse was enhanced by the fact that more culturally diverse families were making use of the services. This was a result of her outreach to the Hispanic community at schools, hospitals, churches, etc. Mary Huber pointed out that as in the case with Bola, the fact that Miriam was hired by the Clearinghouse is a step towards cultural competency.

Also of importance is that a grant proposal written by the College of Osteopathy, which houses the Long Island Clearinghouse, was written to help create a Hispanic School of Excellence in osteopathy. What is intriguing is that this grant would contain funds to further Miriam's work. Mary would like to contact Jerry Blue about this relationship to Partners in Health.

The Long Island Clearinghouse also realized that although it is important to create and distribute materials in Spanish, it is equally important to have someone able to speak Spanish when answering the phones. Simple observations like this often go unnoticed.



### **III. WHAT STEPS DID THE CLEARINGHOUSE TAKE TO LEARN ABOUT THE CULTURALLY DIVERSE COMMUNITY? WAS THIS PROCESS HELPFUL IN IDENTIFYING CULTURALLY DIVERSE FAMILIES WHO HAVE SPECIAL HEALTH NEEDS?**

Miriam:

The methods Miriam employed included public service announcements, print media, and radio ads. Others suggested using Spanish radio stations as well. Miriam also contacted churches, schools, nurses and hospitals. She also distributed materials at Puerto Rican fairs and at shopping centers. Miriam also tried to reach the African American community by contacting and making appointments with pastors. She also sent packets of information to day care centers and churches she could not visit in person. The most productive links she forged were with pastors and churches.

Miriam did not have to "learn" about the culturally diverse community, because she has been a part of it her entire life. In fact, her family ran a local business with both African American and Hispanic clientele. Thus she was able to quickly outreach to culturally diverse communities.

Forced to mention which avenue was the most productive, Miriam responded by citing her visits to La Vita Christiana and Our Lady of Miracles. These were both places from which the Clearinghouse received numerous calls and clients. The Catholic Church has developed its own outreach program, much like case management, and it was very easy and productive to tap into this very organized resource.

Miriam noticed at the prayer meeting of mothers whose children had special care needs, how much the parents shared with each other. These people also told others about the Clearinghouse and the Case Management Program. It was not important to have these people join self-help, because they had already formed their own self-help/mutual support group. Miriam followed up with phone calls and confirmed that these meetings were an ongoing occurrence.

This is an obvious example where self-help has developed a different form than traditional models popular today. Also, the culturally diverse are often involved in self-help through extended families. These extended families provide support, financial resources and baby sitting; these are all services and benefits often associated with government agencies or as a result of support group networking. It may be important to redefine self-help in these environments.

Bola:

The Schenectady Clearinghouse began by formulating a comprehensive list of culturally diverse agencies, businesses, churches and places where the culturally diverse go for help. This informed them of where this culture is located. Through this resource they were able to contact community leaders such as pastors and businessmen. Bola was also able to develop a relationship with the Director of Carver Health Center in Schenectady. This health center is a major provider of health services to the culturally diverse families in Schenectady and Albany areas. This director was very helpful in suggesting means to communicate the existence of Partners in Health.

Terri:

The Niagara Clearinghouse already had access to a resource list, but much of Niagara County consists of rural areas. Many of the residents of Niagara County are forced to access services of Erie County because they are not available in Niagara County. This provided a challenge.

Because Liz was on staff, they were able to present information on Partners in Health to the Native American Community. Liz was able to leave information at the schools, talk to the chiefs and give packets to the churches on the reservation.

In addition, the Clearinghouse contacted leaders of the African American community in the city of Niagara Falls. It became apparent that many people in Lockport, the county seat, were very reluctant to drive to Niagara Falls or Erie County to take advantage of available services. Unfortunately since Niagara County has several smaller urban areas instead of one major center, support services are spread throughout the county. Terri cited a Hispanic woman interested in starting a support group for Hispanic families who could not find enough interested people willing to attend the meetings.

#### **IV. WHICH RELATIONS AND CONTACTS WITH THE CULTURALLY DIVERSE COMMUNITY WERE THE MOST PRODUCTIVE?**

Miriam:

The churches were by far the most productive.

Bola:

Bola believed the community centers to be most productive. After talking with Mary about his frustration related to feelings of failure to communicate the services of Partners in Health to the community, Bola began working with Girls Inc. Girls Inc. is an improvisational theater group made up of young people. Together they wrote and constructed a play which involved audience interaction to give a demonstration of how a support group worked. Once completed, they were able to find an audience of culturally diverse families of children with special health needs at the Christ Church Day Care Center. The families were quite enthusiastic about this youth expression theater and Bola believes if more time remained, this way of communication could have been expanded in a meaningful way. Such a play could have been performed at other agencies on an ongoing basis.

This is another example of non-traditional forms of self-help. Because the actors were trained in generating audience participation, the presentation took the form of a meaningful self-help group. People from the audience began to share real emotions, problems and concerns.

This discussion of Bola's creative form of outreach sparked a debate as to the conception of self-help among culturally diverse. Miriam pointed out that in her experience she noticed a young Hispanic woman referring to support groups as a "white thing." "If a white person breaks a nail, they join a support group." Terri confirmed that she too has found culturally diverse people believing support groups are only for the whites. Terri also pointed out that many whites are transplants and self-help groups provide a resource and way to interact with other people. In many culturally diverse communities, extended families are present locally. In addition, whites are attracted to support groups because the therapy they desire is not available in the doctor's office, while agencies and therapists have large waiting lists.

#### **V. ANY PARTICULAR OUTREACH OR KEY PERSONS THAT HELPED YOU REACH THE CULTURALLY DIVERSE FAMILIES?**

Terri:

Terri struggled with this question because she did not honestly feel they reached the culturally diverse families. Liz helped them make information available to the Native Americans, but in general, it was very difficult for them to reach the culturally diverse families.

## **VI. HOW DID THE PROJECT PROVIDE OUTREACH TO CULTURALLY DIVERSE FAMILIES?**

Bola:

Bola tried most available mediums to reach culturally diverse families; he even went door-to-door. He found placing an ad in the Albany Times Union, a local paper distributed to the entire Capital District, generated a response. He believes he has reached many culturally diverse people with information, but he is not sure what they will actually do with that information.

## **VII. WERE THERE ANY MEANS OF OUTREACH ONE WOULD CLASSIFY AS UNSUCCESSFUL?**

Terri:

Terri cites a three part series of sessions they designed to train parents to become parent advocates. It was unsuccessful in that it failed to attract culturally diverse parents, even though that was the explicit target audience. Only one culturally diverse parent (aside from Liz who attended because it was her job) actually joined the parent advocacy group.

Bola:

Bola found running an announcement on a Community Cable Access Station was a waste of time. He did not receive any calls from that ad.

Miriam:

Miriam found that sending packets to people giving instructions as to how to begin a support group did little good. Despite calling to confirm receipt of the packets, little or no initiative occurred.

Bola believes when trying to perform outreach of this kind, it is very important to classify which media forms will reach the targeted population. Miriam confirmed that she garnered responses from local Pennysavers (small, free newspapers).

**VIII. WHAT STEPS DID THE CLEARINGHOUSE TAKE TO ENHANCE THE CULTURAL COMPETENCY OF EXISTING MUTUAL SELF-HELP SUPPORT? WERE THESE APPROACHES SUCCESSFUL?**

**Bola:**

At the Schenectady Clearinghouse, Bola found it necessary to update the self-help directory. He used this opportunity to give support group facilitators information on attracting culturally diverse families. He felt that some self-help groups were very interested in attracting culturally diverse families. Bola tried to make it clear the services of the Clearinghouse were at their disposal.

A major effort to improve cultural competency of self-help groups occurred at the conference on chronic illnesses. The morning session was devoted to explaining the merits of support groups while the afternoon consisted of a fair where representatives from various support groups handed out brochures and were available to answer questions. This conference was held in Arbor Hill, an area in the city of Albany made up of predominantly culturally diverse families. All the support groups for families with special health needs attended. Unfortunately few families attended. This was probably due to a major community event occurring the same day. In the future, one must check the community calendar when planning such events.

**Terri:**

When hosting support group leader training, Terri uses that opportunity to discuss cultural diversity. She tries to make participants aware of cultural diversity seminars and encourages attendance.

**Miriam:**

Miriam honestly replied that she was unaware that this was a goal of Partners in Health.

## IX. SHORT- AND LONG -TERM IMPACT OF THE PROJECT

Terri:

The greatest impact Terri viewed came from the connections they forged with parents who became advocates for special services from the schools. Through the parent advocacy program, they empowered many individuals as well as support groups. These parents also began demanding information and care from the medical community. These parents may change the system and thus make it more beneficial for all families, including those who are culturally diverse.

As stated previously, a great impact of Partners in Health is the increased cultural competency of the entire staff at the Niagara County Clearinghouse. They have also constructed a current directory of self-help groups which will have a lasting impact.

Bola:

On a short-term basis, Partners in Health in Albany County increased the awareness among culturally diverse families of the nature and existence of self-help support groups. Bola was providing a definition of self-help/mutual support which did not even exist for much of the culturally diverse community. Bola also feels that they improved the cultural competency of many of the agencies they came in contact with.

On a long-term basis, it is difficult to make an assessment. As stated earlier, Bola knows many people have received information about Partners in Health, but the question remains as to whether these families will actually call the Clearinghouse. Also, contacts made with community leaders may have a great impact in the future.

Miriam:

Miriam feels that contacts made from her outreach to the community had quite an impact. Many families from Long Island received information and then were able to receive the help they needed through the efforts of the Clearinghouse.

The long-term impact is that families received information on the self-help services they are entitled to. The Long Island Clearinghouse has helped bring many people into the current system of social services. Unfortunately, the Long Island Clearinghouse does not intend to continue the project due to a fiscal crisis. Because of this crisis, the major impact of Partners in Health will be seen in the Case Management Program. Partners in Health and the Case Managers established a strong relationship, and often referred services to each other. Today, because of Partners in Health, the case managers are more aware of cultural issues and have agreed to recommend self-help/mutual support.



This may be the case in Albany and Niagara counties as well. It is hoped the case managers will continue to educate and advocate self-help to all families, especially those that are culturally diverse.

#### **X. WHAT ASPECTS OF THE PROGRAM CAN BE LABELLED INNOVATIVE?**

Terri:

Terri stated the policy of reimbursement of travel and child care expenses for Partners in Policy Making as innovative. This policy was adopted by the Parent Advocacy group and made a difference in obtaining participants.

Bola:

The very flexibility of the program allowed Bola to try innovative outreach, including the improvisational theater group.

Mary:

Mary Huber stated this project had a major impact on the New York State Department of Health (NYSDOH). This whole notion of working with parents is a new concept at the state level. This project has given them knowledge of how to support and initiate parent-to-parent programs within the state. The project initiated an entire new thrust within NYSDOH. They did not know how to involve parents in policy making concerning self-help groups. A similar occurrence was realized in the area of cultural competency.

The initiation of programs where consumers of health care work together with NYSDOH in policy making is quite new and a result of this project. A particular example is the Physically Handicapped Children's Program. The creation of the support group directories proved to be enlightening to state agencies as to how many parent resources were already in existence and available. Bola commented Partners in Health helped many people become initially aware of the Physically Handicapped Children's Program.

## **XL DID YOU FEEL THERE WERE SUFFICIENT STAFF AND FUNDING TO OPERATE EFFECTIVELY?**

Miriam:

Miriam stated the Clearinghouse was understaffed and she needed to work more hours. Seventeen hours a week is just not enough. She also pointed out house visits are not permitted and that many people cannot read English. These people have no idea as to how to fill out an application. For them to acquire the services she offers, she needs to go to the actual home. One can not do that with only seventeen hours a week. Miriam also found the number of phone lines to be inadequate. Many calls do not get through because she often spends a great amount of time speaking with an overwhelmed parent. She certainly can not hang up on these people in case others are trying to get through.

Terri:

Terri claimed they had enough financial resources to fund the programs, but not enough staff to meet the needs.

Bola:

Bola saw a definite need for a full time coordinator for the program. Without a full salary, the person is forced to find other means of supplementing his or her personal income which distracts attention from the program. The coordinator should be well trained in all aspects of support group processes and formation.

## **XII. LESSONS LEARNED TO BE APPLIED FOR REPLICATION AND TRANSFER**

Miriam:

Miriam learned quickly that families with special health needs are too overwhelmed to be interested in support groups. It is therefore critical for professionals in various agencies to verify that the clients are receiving all the necessary and desired services. Professionals must also follow up to make sure clients are not abandoned by the system.

### **XIII. WHAT CHANGES SHOULD BE MADE IN THE PROPOSAL?**

**Bola:**

Bola believes it necessary for the project coordinator at the Clearinghouse to be a troubleshooter and facilitator for the support groups. He believes the coordinator should actually lead the group in its infancy stages and then draw back slowly as it becomes self-sufficient. This was not the practice of the current project and in Bola's opinion was a definite hindrance in attracting culturally diverse attendance.

Bola would also like the Case Management Program and Partners in Health to work even more closely if the program were to be redone. In his opinion, the goal of both programs is the same, and perhaps it would be mutually beneficial to be housed together. If this project were extended they could spend more time forging the partnership with case managers. Miriam agreed with Bola completely.

In the beginning, the case managers looked at Partners in Health as one more agency that would distract them. They were worried their workload would increase, but they would not receive any additional funding. It took a significant amount of time to overcome this bias and to discover how mutually beneficial each program was for the other. Also, the role the case managers played was not large; they needed only to refer clients to the Clearinghouse. Unfortunately it took time for this to become clear.

**Terri:**

Another recommendation Terri makes would be not only to target families of children with physical or physiological health needs, but emotional health needs as well. Training for group leaders, parents and doctors could serve an important need in this area. Even with the more traditional health needs, training should be available for teachers and doctors to make them better professionals in dealing with special health needs.

This project also needs more time than three years. Just when programs begin to have positive results, it ends. This is not a realistic time frame in which to make an accurate assessment.

#### **XIV. DOES THE CLEARINGHOUSE HAVE PLANS TO CONTINUE THE ACTIVITIES INITIATED BY THE PROJECT?**

Terri:

At Niagara County services will continue only if they receive a NYS Developmental Disabilities Planning Council grant. This grant would expand the Parent Advocacy Network.

Bola:

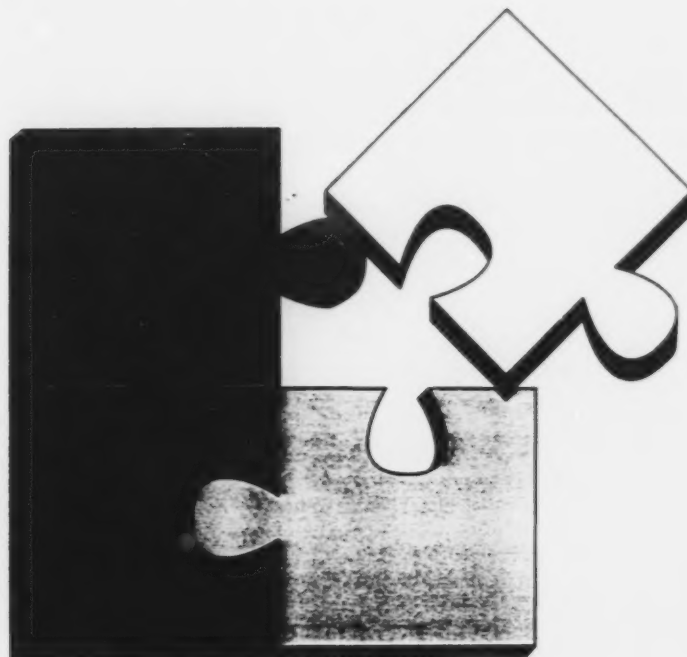
The future of the Schenectady Clearinghouse itself is unclear, but as it stands now the only way to keep the program working is to mail a packet of materials to those who wish to start a support group.

Miriam:

The Long Island Clearinghouse is experiencing a fiscal crisis. She states it needs permanent financial backing. The program will not continue if the Clearinghouse does not.

All the participants feel even if the Clearinghouses and project do not continue, the communities in each area have received a great amount of information on self-help. As an education campaign they were very successful and it was now time to see if people utilize the available services.

**Case Studies:**  
***Interviews with Two Families***  
***Who Participated in***  
***Partners in Health***



New York State Department of Health  
Bureau of Child and Adolescent Health

INTERVIEW WITH M. CALLENDER

CONDUCTED BY MARY HUBER

JANUARY 31, 1994



## INTRODUCTION

M. Callender first began working with the project, Partners in Health/Self-Help Mutual Support for Culturally Diverse Children with Special Health Care Needs and their Families, when she participated in Partners in Policy Making in the fall of 1992 conducted in New York City. In order to protect their anonymity, the names of parents M. Callender talks about have been changed.

Mary Huber: How did you find out about Partners in Policy Making (PIP)? Why were you interested in it?

M.: I was vice president of the Parent Teachers' Association (PTA) at Matthew's school. I had indicated early on to the teacher liaison of the PTA that I was interested in learning as much as I could about different programs and any support systems that were out there to further educate myself and to do my job as vice president better, which was a two-year appointment. She got a flyer about PIP and gave it to me. The deadline was that day or something, but she really encouraged me to do it. She had heard about the program and she thought I would really benefit from it and be a good candidate to do it. So I filled out the application and sent it in. The application was kind of long, and I remember thinking they're probably not going to accept me. First of all, it's the last day to hand it in and because of Matthew's illness. I never looked at it as being chronic; it was just this illness he had. I thought it would be a good place to meet other parents and I missed doing that. And also what interested me was that they had talked about taking the next step, to get involved at the government level, of making changes. By this time I began to get interested in learning how government worked, and how laws worked, and with the elections coming up, I thought it would be a good time to get more involved.

Mary: You were very active, for example, you were vice president of your son's parent group at school. What did you learn at PIP

that was new for you?

M.: First of all, the main thing was that thinking prior to that, even though I was very involved with Matthew and within that community, I was still feeling that you're just one person, and one person cannot really make a big difference. The thing I got out of Partners was that one person can make a difference, and that one person is also one vote, one letter, one contact with a public official. Any thing one person can do can really help bring about change. That was the main thing. Also just to have the confidence to just go ahead and do it; not just talk about what is wrong, or not just to talk about what you would like to see happen, but to actually use the tools to go about making the change. To do something as simple as an outline of how to write a letter to a representative, or to a school board person, or how to approach someone correctly so if you have only three minutes to talk to someone you have to get an agenda out and figure how to do that. So it was those tools that became very important. Of course the vast information was very overwhelming at first, but seeing the other parents who were presenting made me realize these are people who, like me, never thought they would be doing this, and they are really making changes. That was the first main thing for me.

Mary: Were you able to make connections with other parents as well?

M.: Well what happened was that I am still in contact with the

parents who were there when I was there.

Mary: In what way?

M.: Really for support; they are doing a lot. They have a lot of resources. So if I need help with something, actually something came up on Friday and I am going to call people this week and see if I can get help. They are always more than willing to help out. Usually it's finding out about community programs or what supports are out there. It's been kind of a switch; now I am getting those calls too. People are now calling me for support or asking hey, do you know about this or how can I get involved in this, or can I help them -- which is a little bit of a change. So for support, for help, I call them periodically to say hello, to touch base, to network because, especially now, with my job I am doing a lot more community outreach. Some of the parents are really active; they are the ones going out for the grants now to start programs.

Mary: Can you give some examples?

M.: A couple of the parents, for instance, in the Brooklyn area ... one of the things they are doing is going out for these grants which come up for programs. It seems now parents are taking the initiative for these programs as opposed to professionals which is a switch that I have seen over the past year, parents are really looking at making programs truly inclusionary. Bringing their children into the community ... not

just in a school setting but having the community be a community, in a church setting or in a grocery store setting or a library setting. Really to make the community aware that their children are a part of the community. This is just a little bit different than a school inclusionary setting.

Mary: So it's more holistic?

M.: Yes, definitely, definitely.

Mary: That is an interesting comment, because it really is talking about systems change and this whole phrase community based, and so forth. It's really putting that sort of thing into practice.

M.: Yes, definitely. They mean it's not just about having the children in a classroom setting, but also working on a day to day basis, not just with their children, but with all children. And really including the community, which is very exciting. Again, they are going out for these grants now and their information is really amazing how much they are able to find and go access. There are some educational models and they are now working on health projects again too. So there are a lot of different projects they are working on, but not only for their children with the disability, but also for the community as a whole.

Mary: Now how about these health issues? Can you think of some examples on what they are working on there? That is new to me.

M.: I know one person I spoke to was trying to actually go out to some health clinics and centers throughout the community and trying to get their own mini grand rounds going which is interesting. And this is on a cultural level as well, of being more respectful of parents and their families in the doctor-patient relationships, which still seems to be an issue. But even beyond the physician, it's in general.

Mary: I think Ralph Smith talked about doing some of that.

M.: Yes, Ralph was one. Reverend Peters is working in that area as well. She lives in the Bronx. But this is something that has to do with physician-parent collaboration. They are thinking at more of a systems level. At a grand rounds doing it at a mini level. These community health centers play an important part in administering preventative health care in the community, so they are a very important outlet to use. That is really the biggest trend; and again they are going out, getting the money, getting the grants, and getting the support lined up so they can do this. This is really on their own. A lot of these are programs that they started and they really do not have any big backers. They are going out there on their own. Just the fact that they have the initiative to do it and they are doing it. These are the parents I first met at Partners and it's not even been two years; a lot of things are happening.

Mary: In New York City too, where people say nothing can happen?



M.: Yes, yes.

Mary: How about yourself personally, what has happened to you personally since you went to PIP? What changes have occurred in your life?

M.: The first thing is really taking an active role as opposed to passive one in our political system. After Partners, rather than just going to vote, I actually began listening to the people who are running in Washington, the State, and reading articles, and being able to make a more quality judgement rather than just voting for a particular party or particular administration. I was able to make an intelligent decision of who might be the best person in a particular office. Along with that is becoming more aware of things that we need to change and be more sensitive to those needs. Not just my own needs. By this time Matthew was already gone, so I wasn't doing it anymore for him, but realizing that these needs are still out there, that you really need to be a part of the system changes. It's about waving a flag, getting on a soapbox, about being a part of the system and realizing, indeed, you have a voice that can be heard and it can make a change no matter how little or big it is. You have to be involved. You have to deal with it with integrity, and honesty, and at times there is a little soul searching involved. Because all of a sudden after being in the presence of the President people turn to me and say, "Well, what do you think?" [As M. explains later in this interview, she met President Clinton.] I

realize sometimes you have to choose your words carefully or really look at the whole picture and not always make it, well, this is what I think, this is what my views are, but really look at a global point of view. For example, something came up on Friday about inclusion and there was a huge discussion, pros and cons, and I was very honest at one point. I said, "Well you know with Matthew I was not going to put him into an inclusionary setting, it was not what I wanted with him." My husband and I wanted him in a special school and so forth. If I had to do it now, there are more choices available; I do not know if I would make those same choices that were made.

I was asked to write an article for a well known publication against inclusion, and I had to sit back and think, "Am I against inclusion now in 1994? Am I really concerned about the state of our school system and how they really need to change?" I'm really concerned about school in the United States not being good for healthy children much less a child in a wheelchair. I won't say people do not want to hear that, but it might be, "Well, that might be true," but inclusion is a very big trend and I'm thinking well, yes, but we have to think about our school system before we take away the choice of parents, and inclusion may take away the choice of parents. So it's not outright to say I am not for inclusion, but I do think you have to look honestly and with open eyes at a school system which in many areas is not safe. You cannot tell a parent of a child with a disability in that

neighborhood this is where your child has to go to school. They have to have a choice, of well, I do not want to send my child there, I'd rather put him on a bus for an hour to go to a specialized school. So it was that kind of growth that happened that has broadened me.

Mary: We have not talked about some of these other things that happened. You got this whole new job, for example [M. is employed as a family specialist for the state's Part H program.]

M.: That came about from meeting two parents that weekend who I thought were both remarkable women. Beth got a flyer for the job and so did Nancy. They both called me.

Mary: They both did?

M.: Yes, they both called within ten minutes of each other. I was hesitant because I hadn't worked in five years. This was a one-eighty from what I was doing. I used to be nervous doing public speaking and meeting important people and I said, "No, this isn't me." And the deadline was yesterday and I had to do my resume and I hadn't done anything in this type of work and I said, "Oh let me send it in anyway." They called me. Oh, and another thing, they were looking for someone bilingual.

Mary: Are you bilingual?

M.: No, I am not.

Mary: That is why you hesitated?

M.: Yes, and that was the other thing. To top everything off I only speak English. But I sent it in. I thought, if they call, fine, and they called. I went down and they gave me the job description. They said, "Well, there will be a lot of public speaking, a lot of training." Then they asked me what my background was, and I told them I was active in the theater, and they said, "Well, you're probably used to seeing a lot of people and talking to all kinds of people, so it's really bringing out your talents." Then they asked me very specific questions about Matthew, how comfortable I was speaking to physicians, what my attitude was about that relationship, how I felt about the different services that were out there. At that point it was to just be as honest as possible. They did ask if I was bilingual, and I said no. They said they were interviewing people who were bilingual. It was a very positive interview and they told me it was the best of both worlds. I could be home by 3 o'clock when my child got home, there would be a lot of running around but it would be the best of both worlds. They called a couple of days later to say I was hired, and they hired another parent who was bilingual. ...

Mary: And they've been happy ever since I'm sure.

M.: Yes (laughing) for the most part except when I get too revolutionary.

Mary: Right, just keep a lid on it.

M.: I am learning. It's really a godsend. After Matthew passed, I don't know what I would have done without that immediate position to go to. It kind of gave, on a certain level, yes my life had purpose anyway (I was married, I had a small child), but it gave greater purpose.... It was a way of carrying on what I had already started because of Matthew. So I was very thrilled and happy, and even now it's still wonderful and a real positive part of my life.

Mary: I also noticed when we were together at PIP meetings that you were a help to other parents who were perhaps not as assertive as you at trying to get services. That you were already a natural helper, and I was especially interested in seeing you work with other black women. I think that they were really willing to listen to you. Can you talk a little about that?

M.: My Mom always says I grew up with very positive role models, my mom being first. My mom is a physician and until I was five I thought all physicians were black women and mothers. Those were the women I saw, my mom and all her friends just happened to be black women physicians who were mothers. So I knew these role models, and I guess certain things are innate; I just do not think about them. I think that it's important that if you are in certain conditions that you help other people, that is the other side of it. You're not just out there alone, you have to encourage and help other people. I think coupled with that,



those two things, working together and constantly listening and translating things for people, and being a role model and the responsibilities of that. Obviously, I am quoting you and I am going to paraphrase you, that people look at you, they first look at you because of who you are, but they'll listen to you when you start to talk. Again, when you realize that happens, again you have to use it in the right way. Whenever I do public speaking, or whenever I do something special, and I know there is going to be more of an Afro-American population there, then I do go out of my way to look as nice as I can, to project a positive image, but also to be acceptable to them.

When Shirley asked me to speak at the last Partners [in Policy Making], a very funny thing happened. That was an amazing, amazing personal thing. It was like coming full circle and I was talking about doing a speech I had done several times during the year without it being rehearsed or a routine kind of thing. When Shirley gave a gorgeous intro, I was wondering who she was talking about, then I got up. At one point inside I just got emotional and I was talking to the crowd, but also to myself and it was amazing what went on. People were listening and crying and applauding all at the same time, and it was this kind of amazing situation. At the end, I did say Matthew passed away, but this is what I have done since then. I showed them the clips from the paper with the President. I explained that I was pregnant again, and I got this applause and it was just a very intense fifteen minutes. But afterwards it was as important that



I be accessible. It was very interesting for me to see how people approached me after that, almost nervous to come up to me. And since everyone had name tags on, it was important to say "Hi, Dorothy" - just to make them feel comfortable and to listen to them and if they wanted to cry, to let them cry; if they wanted to ask questions, to let them ask questions. Many of the women there were thinking about having other children so that was important. My daughter was there too....

Mary: So they were really talking to you about some serious things.

M.: Yes, I remember when I was in their situation a year ago, that not everybody is as accessible or is as, well, almost gracious, and realizing that you want to talk to them, to the person who just gave the speech. So I keep that in mind, too, that you want to be accessible and make people feel comfortable with you. And again that is part of the whole role model thing of being an example. Not that that is a reason ... to be positive or negative. But it is important to be a positive role model and to make people feel comfortable. And again too in this society, I think there are so few Afro-American role models. On the phone, people do not know whether I am black or white. I was calling these parents. I could tell they were thinking, "Here's another person calling from the Department of Health calling me and asking questions." I just called to introduce myself, we're having this forum on Friday, do you have any questions, do you

feel comfortable. I give my phone number, which I do not give out to people, but in this situation I did, and said give me a call if you need to talk. On Friday I got a little more dressed up than usual, but again it's to look nice. I walked over to the parents and said, "Hi, I'm M. Callender," and they were like, "Oh!". You know, it was that kind of reaction.

A couple of parents were very angry, they were ready to fight. So it was very important at that time to really make them see we were really working for a purpose. And again, afterwards, even though people were there who had much more Department of Health experience than I have, ... the parents who were there, who were primarily culturally diverse minority parents, were asking me, "Can I come speak at a program, Can you come see my school, Can you come to my church, Can you come out and speak?" So there is a need to identify. And that is part of the program. You know they want to identify. I have to give a positive image, and it goes a long way.

Mary: One of the thoughts behind doing this project, Partners in Health, was that we wanted to engage culturally diverse families in parent to parent support because parents can be so helpful to each other, but we also knew culturally diverse families often are not a part of these parent groups. So that is really what we wanted to see if we could do something about. And it appears when we look at what happened with families who participated in PIP, now that we've got the evaluation tools in place, that the

culturally diverse families got just as involved, if not more so, than the Caucasian families, which I think is really great (M. agrees). But also, I always picture this like the layers of an onion, and we were able to get into PIP culturally diverse people who were more acculturated, and they are like the outer layers of an onion (M. agreed) and then you folks act like the messengers to those who are on the inner layers.

M.: Many of those in the inner layers are still very skeptical, very fearful or angry.

Mary: Yes, and I think what you have described beautifully is that process taking place. Now you are there in an accessible manner to other culturally diverse people who can relate to you much better than to someone else who is not culturally diverse. Is that a fair interpretation?

M.: Oh yes, definitely. There is a responsibility with that. I am not sure that it's, how to say this, it's unfortunate that it's like that still, but that is the reality. It's something that you have to be conscious of.

Mary: Is there anything else that you would like to talk about. We never really talked about how it happened that you got to talk to the President and what that did....

M.: Well, I got very involved with the election and felt that I had a part in putting Clinton in office. And I watched all the ceremonies, the taking of the oath of office and what not, and

really feeling that even if things were not going to be perfect overnight, it was at least a movement in the right direction. Shortly after he took office, and he was setting up all these different task forces, the health task force, one of the things he said was that he and Hillary could not possibly know what everybody in this nation needed, and what they were going through, and the only way they could do that was to go over letters. He said people should let them hear what they are going through.

So I sat down that night and wrote a letter. I'm one of those people who have had an experience, so I wrote using the PIP guidelines, but I did break the rules because the letter was more than a page and a half, it was three and a half pages ... and that was cut down from an original draft of ten pages. I don't think I would have written that letter if it were not for Partners. That was back in February 1993. In August, we got a very beautiful card thanking us for the letter and acknowledging it. I thought that was it. In September, we got a phone call from the White House; and also one of the things Partners did was to tell us to send a picture, and I sent the Christmas picture, one of the last pictures of Matthew, a very beautiful picture of him.

Mary: Is that the same one that is in that book now? [The brochure published by the White House describing the President's

plan for Health Care Reform.]

M.: No, that was part of it - there were three pictures, a family picture, a picture of both Matthew and Melissa which was a gorgeous picture and then one of him .... I do not know if I sent the picture of Matthew and Melissa.... And I don't know how I said it in the letter, but I think in the last paragraph I said Matthew had passed. So it was like building up to that, and there was the picture. And the person said that both the President and Mrs. Clinton were moved, and that it would be an honor to meet with me and several other parents on Sunday.... And of course I said yes. The other joke that I always tell was they were trying to reach me for a week, but they had my fax number and my message number because I also sent my business card, but they were not able to reach me. I guess the White House does not leave messages. And the joke was that they said, "Well, we could not reach you at these other numbers but we were able finally to get your number," which is unlisted, so I thought that was kind of big brotherish. I wondered how they got this number.

And the next three days was total shock. I don't think I slept in three days. Then we were debriefed and everything. I asked if Mark and Melissa could come because I realized that if Matthew were alive he would be there so I wanted to have Mark there. It was just amazing. Then moments before we're going to our security area,... it was at that time they told me I would be sitting next to President Clinton. So that really, whatever



strength I had left was gone at that point. And it's really just an amazing honor. The first day you get nervous, and then you go jump around, and then the motorcade starts, and it's like I'm going to be in there - I'm going to meet the President. I remember calling you and Shirley - I'll take my little camera, and I'll try to take pictures .... There was a disappointment, they were running late. Three of us were to speak privately with him, and that never came about because he was running late. After I read my letter - well actually when the next person was talking - he leaned over and said a few words to me. He asked me, very briefly, "Well, how are things going now?" And I was thinking I have three seconds to tell him how things are going. "Well," I said, "we still do not have health care, but this is really a new day and Matthew is a constant reminder of what needs to happen." And again, it was brief and he thanked me again for being there, and that was it. It was quite a day and quite a week. It changed a lot. It really did. I had to be in Albany the next day to be with you.

Oh, I know, the White House called Monday morning at 7:00, and said the President was very happy to speak to me and he has these books going out. They were supposed to go out the next day, but he put a hold on it because he wanted me and my family to be in this book and they'd send a White House photographer to take pictures. By this time, I'm bezerk, and still kind of frazzled, and I said, "Well, I had a radio phone interview to do



and I was on my way to Albany." They said, "Do you have any recent pictures that include Matthew?" Luckily, I had those Christmas pictures. So I had to go to my husband's job to find them. When I got out of the cab and saw a newsstand I said, "My God! I made the cover of every newspaper." I got to his job. His job is usually pretty busy so it wasn't unusual to see quite a few at the counter, but when I walked into his job (he's the manager), he looked at me totally exasperated, and I said, "What is wrong?" And people said, "Oh, this is you." He said everyone was saying, "Is this your wife?" and it was an incredible mob scene. Later on that night, after I got up to Albany and after I relaxed, I called. He had to leave work early because he couldn't take it. Then of course the movie came out of that [a producer asked the family for the rights to tell their story for a television movie].

So for those two to three weeks afterward, it was like you don't know what is going to have an impact. But it really did. And again, it's just a continuation of you can make a change, and again, make a positive change.... like Martin Luther King.

My situation with Matthew makes me feel like a Coretta Scott King or a Dr. Shabazz. This is your road in life, to lead.... to speak. You're going to champion the people. It is that kind of parallel. It doesn't end here with Matthew not being here anymore. Even one small voice is still a voice, you just keep

working and keep going. It's nice to see little changes that happen....

Mary: The thing I wanted to ask you about, and I think it will be the last thing, is this whole issue of cultural competency, and how you have grown with that? It sort of seemed like this was kind of a light bulb for you.

M.: Oh yes, it's always been an interest and I've always loved traveling not just not superficially but on a another level, especially in relationship to practices that people live every day, and how that related to health and how child care evolved, and it's grown from there. The only way to be able to help the families is to really learn the culture and really understand it. I don't think that learning to be culturally competent means that you are excluding or segregating a culture, it's just to help enhance your understanding of people in general, on a much broader level. And you get that sometimes when you deal or speak about cultural diversity, cultural competency or cultural sensitivity. People are automatically thinking you are trying to segregate or separate, and it's really not that at all - you're really bringing cultures together. I told you the story when Matthew was first born and the rabbi came into the room? (Mary: Yes, that was quite a story), yes, and that wasn't a separate thing. It was a culture that put a lot weight on having sons, and even though, obviously when he saw me, he knew I was not Jewish, still he blessed me and my son and when Mark came in I

could say, I have given you a son - which is very important in the African-American community as well. Then Mark took Matthew and held him like that famous scene from Roots, where the guy holds up the son to the moon. And I said, "If you drop that baby you're out of here." [Laughter] But again it's a meshing of cultures, not a separation of cultures. I think we have to, as a people, understand that.

Somebody, one time said, something very interesting, that part of the problem with Clinton's health plan is that he is calling it universal health plan. People are not comfortable with being part of a whole, and the word universal could cause problems with how people perceive themselves. You do not want to be put in the same category for instance as, an AIDS patient, or a physically disabled child, and so forth.... You know how people are very sensitive about losing identity - not realizing the more you know, the wider, the bigger awareness you have. I don't know, before we got pregnant I was thinking about one of the things I was interested in doing was getting a grant to actually study different cultures, to go and live on the reservation for awhile, and live on a kibbutz, to go to Africa. A very good friend of ours was in Botswana for many years working over there, and again just to really learn about the people, not just the language. So I think it's very important. I definitely think it's a trend, or not just a trend, but a direction in which things are going. One of the schools I hope Melissa can get

into, is the U.N. school. I want her to be in that kind of setting. I really think as we go into the twenty-first century, that is the only way we're going to survive, not only as a country, but on a universal level. People need to feel comfortable and not keep having a separatist attitude.

Mary: You also helped us with training on cultural competency. What was that like for you?

M.: That was really educational for me. I think all these things are such a learning process for me. I think it's important to look at yourself very objectively at times; to see the good points and the bad points, where the strengths and weaknesses are....

When I went to Bellevue [Hospital] and saw the attitudes there - you're black, at a clinic, then you're obviously on welfare. If there is a pregnancy problem, you're no good, you're ignorant, and you do not deserve respect. I went outside to the waiting room. I would say that of 80 percent of the people there, English was not their first language, and how were they treated when they walked in there? And if they are of different cultures, and still very new to this country, and have not adapted to our Western ways, they are viewed even more in a negative light. When I do these cultural competency seminars, it's really a learning experience, to broaden what I know, what I see, and how you see yourself in relationship to other people,

and how you can help change the system so they are not alienated if they are of a different background or speak a different language or have different supports and belief systems.

Mary: Well, that is lovely. I can't think of anything else. Is there any summary statement you would like the funders of PIH to know about?

M.: I think that it's just that it opened so many doors for me; that it was a natural stepping stone. I have come so far, and it just elevated my confidence. People just have so much to offer. And parents really live and breathe this 24 hours a day when they have a child with disabilities, but that doesn't make us immune to being able to fight to do what we need to do for our children. It's important to have programs like this, because if you have 50 parents, they can reach 50 other parents, ... and then you'd get a positive thing. It really does develop a network.

Mary: How many parents do you think you have reached?

M.: Oh wow, I would say close to 1000 by this time. That's not counting - still when I do my work, when I tell people my name, they have my face on their refrigerator, these are the people I don't even know. This woman said, "How do I know you?" I said, "I work here in the Bronx." And at one point they say, "You were the one who met with the President." That I am still getting. I don't know how many people I have reached in an indirect way. My mother's patients will say, "Oh, I saw your daughter, I cried."

I'm still running into people who saw me, and they'll say they have a granddaughter, or a niece, or a cousin, or the daughter of a friend, and they share their experiences. At least they feel that someone is listening. I encourage them to write letters, I encourage them not to be afraid to speak what they want to speak. Get out there. That is the only way changes in the system get made. I give credit to Partners for making me aware that you really have to be a part of the system to change it. Plus meeting you was a real bonus.

Mary: Same here.



**INTERVIEW WITH KAREN MILLER**

**CONDUCTED BY MARY HUBER**

**NOVEMBER 19, 1993**

#### INTRODUCTION

Karen Miller first began working with the project, Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families when she participated in Partners in Policy Making sessions in the fall of 1992. Her name has been changed to protect her anonymity.

CASE STUDY  
MS. KAREN MILLER

Interview conducted on November 19, 1993

by Mary Huber

"Partners in Policy Making has had an effect on every part of my life -- professionally, emotionally and personally." With these words Ms. Karen Miller described the impact of Partners in Health.

Karen is a Native American of one of the Nations of Native Americans in New York State. She is the mother of four children, Child A, a girl age 12, Child B, a boy age 10, Child C, a boy age 6, Child D, a girl age 4. Children C and D are microcephalic, and Child C also has a hearing impairment. Both children have participated in an area early intervention program since they were newborns. This week Karen and her husband learned that their 10-year-old son has been diagnosed with Attention Deficit Disorder. She reported that it was not easy to hear this information. "Even though we have two other children with special needs and we might be used to this, it surprised me how difficult it was to deal with this news."

Prior to becoming involved in Partners in Health, Karen was an active parent. She participated in the mothers' support group at the two younger children's school, and also served as a parent member of the Committee on Preschool Special Education (CPSE) at

the local public school district.

At the time of her application to Partners in Policy Making, there were several educational resources for pre-school children on the reservation -- including Head Start and a general early childhood school program. But there were no resources or programs for children with special needs of any age.

Karen wanted to become involved in Partners in Policy Making so she could learn more about her own children's needs. She also wanted to increase the awareness of her Nation to special needs children. Families are reluctant to reveal that they have a child with special needs and there is no mechanism for child assessments that would assist the Nation in identifying the children. Therefore, at the time of her application, there were no services on the reservation. She could see that two potential allies to change this situation were the recreation and education departments operated by the Nation. In the application to Partners in Policy Making, she wrote that she wanted "to make them more cognizant of our special needs children's various abilities. To do this, we as parents need to work together and make our voices heard." Thus, Karen came to the project with a great readiness to learn and a sense of purpose for new-found skills.

As with parents in the majority population (Karen's words for people who are not Native Americans), at Partners in Policy Making she learned of new resources and developed skills in accessing those resources. She reports that she learned to be much more assertive with the public school system in obtaining

services for her children. For example, the school balked at sending her son with the hearing impairment to a special school for the deaf in a large city nearby, but she successfully persisted in demonstrating that it was the only appropriate placement for her son's needs.

Karen also enhanced her skills as a CPSE parent member, learning to stress the family centered aspects of those meetings. "Now I always insist that parents fully understand what is happening and encourage them to take all the time they need to make decisions. The school district has thanked me for my attention to family concerns."

In addition to enhancing her abilities in her former roles, she also took on a new role as a result of Partners in Policy Making. As part of the training session, Partners in Health encouraged parents to form support groups so that parents could provide each other with emotional support and practical assistance. After Partners in Policy Making, she formed such a group on the reservation. Ten to fifteen families meet on a regular basis and have accomplished several tangible results.

1. In the early meetings, many parents reported they were overwhelmed by the high cost of diapers. At one of the training sessions on cultural competency for which she served as a co-trainer (another activity of Partners in Health), Karen learned that families could access Medicaid funds to assist with this expense, and families are now doing so.
2. Families discussed the need for recreation facilities. In

concert with the director of recreation at the reservation, they developed a therapeutic riding program at a nearby ranch that is available at no expense to the families for children ages 2 and above.

3. The Nation has placed special physical education equipment in the community building so that children with special needs can play too.
4. Through Karen's encouragement, the director of recreation for the Nation became a member of the board for a local community-based organization for the disabled. Through this organization, the Nation began discussions to obtain resources to set up a swimming program, especially for children with spina-bifida whose families are particularly reluctant to allow them to swim. Funds will provide for a swimming specialist who will supervise the children in the summer at the reservation's pool. Special equipment will be purchased to lift those who need it in and out of the water. The lifts will also be used by senior citizens, many of whom are disabled as a result of diabetes.

I asked Karen if all of these things were due to her efforts, and she said that she had never thought about it, but she guessed that was the case.

I was interested in learning whether the support group on the reservation was any different from the one she attended in public school. Karen said, "Our support group is more like a family because many of us are related or have known each other for a long time." We speculated about whether this familiarity



was one of the reasons families were reluctant to identify their children as having special needs. Karen thought this was a possible explanation.

In addition to working with the directors of education and recreation, Karen also brings the issue of special needs children to the governing body of the tribe. The Nation has had a democratic form of elective government for over 150 years, with a written constitution, an elected president, treasurer, and clerk, an elected council and a formal judicial system. Last week she met with the newly elected tribal president, who, she said, really listened to what she had to say. Other tribal policy makers that she has contacted are members of the tribal council whom she has met individually and addressed at council meetings. The annual tribal budget will be up for discussion soon, and she and other families will be pressing their case to remind the leaders of the needs of special children.

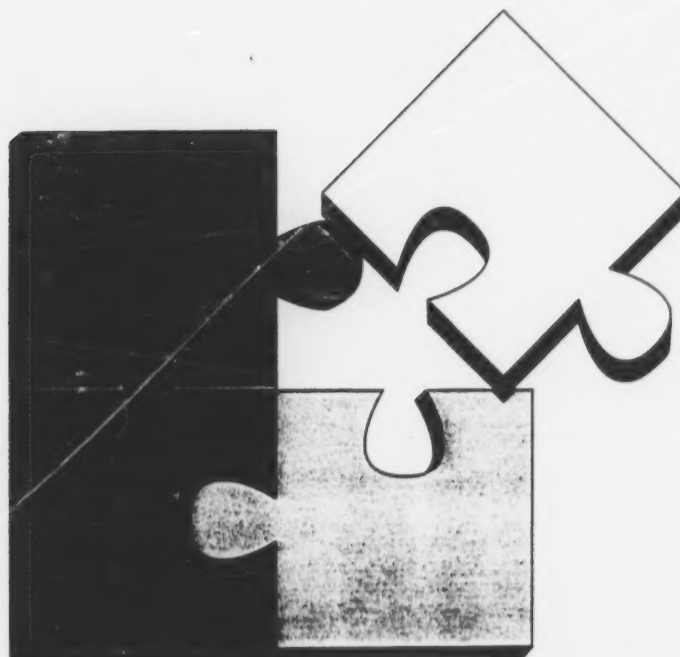
She had found other ways to contribute to improving the care of children with special needs. She served as a parent consultant to the Early Prevention Program of the State Health Department (DOH) as a member of the task force DOH established to recommend payment methodologies to reimburse adequately the cost of early intervention services. She has also served as a parent consultant for training facilitated by Partners in Health on the topics of parent empowerment and cultural competency. Participants were service providers who work with families whose children have special needs. She is encouraging the Nation to expand its horizons in the area of education by becoming better

informed about the three public schools that children on the reservation attend.

Last summer the Nation sent her to a residential training center for Montessori teachers so she could improve her skills as a teacher at the reservation's pre-school program and eventually become a qualified Montessori teacher. She sees the Montessori techniques as especially suited to children with special needs, and believes the Montessori method will assist the Nation in identifying special needs children, such as those affected by Fetal Alcohol Syndrome, who currently may be undiagnosed.

Karen also has a dream for the future, a Special Olympics for Native Americans, which she sees as particularly suited to American Indians. "Even more than members of the majority population, Native Americans are proud of their sportsmen," she explained. She would like to begin this as an activity for members of the Iroquois Confederacy, which consists of the Mohawk, Oneida, Onondaga, Cayuga, Seneca, and Tuscarora Nations.

# **Program Announcement in English and Spanish for Partners in Policy Making**



New York State Department of Health  
Bureau of Child and Adolescent Health



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Lorna McBarnette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

9 de enero de 1992

Estimado/a amigo/a:

La Junta de Planificación para Personas con Trastornos de Desarrollo Físico y Mental del Estado de Nueva York y la Oficina de Salud para Niños y Adolescentes del Departamento de Salud del Estado de Nueva York están patrocinando un programa titulado *Socios para la Elaboración de Planes de Acción* (Partners in Policy Making), cuyo objetivo es capacitar a líderes entre los consumidores. El programa se llevará a cabo del 3 al 4 de abril y del 1º al 2 de mayo de 1992 en Albany, Nueva York, y está previsto para 50 personas de familias con hijos que necesitan una atención médica especial, con particular énfasis en familias de diversas culturas. Queremos hacer notar que la participación es gratuita.

El objetivo del programa es dar a las familias con hijos que necesitan una atención médica especial la oportunidad de participar en la elaboración de planes de acción. Le rogamos que lea la Hoja de Datos adjunta para informarse sobre los detalles al respecto.

Adjuntamos a la presente un formulario de inscripción en el programa. Para seleccionar a los participantes se tomarán en cuenta la calidad y el contenido de las solicitudes de inscripción, las cuales deberán ser echadas al correo a más tardar el 10 de febrero de 1992.

Será una excelente oportunidad para conocer a otras familias con hijos que necesitan atención médica especial, adquirir nuevos conocimientos, capacitarse para abogar más eficientemente por los niños y adolescentes con trastornos de desarrollo físico y mental y asumir papeles de liderazgo en la elaboración de planes de acción.

Si desea hacer alguna pregunta, puede llamar a Mary Huber al (518) 474-6781.

Atentamente,

Mary Huber  
Oficina de Salud para Niños y Adolescentes  
del Departamento de Salud del  
Estado de Nueva York

Shirley Reynolds  
Junta para Personas con  
Trastornos de Desarrollo  
del Estado de Nueva York

## **HOJA DE DATOS**

### **SOCIOS PARA LA ELABORACION DE PLANES DE ACCION (PARTNERS IN POLICY MAKING)**

#### **PROGRAMA DE CAPACITACION PARA FAMILIAS CON HIJOS QUE NECESITAN UNA ATENCION MEDICA ESPECIAL A FIN DE QUE PUEDAN INFLUIR EN LA ELABORACION DE LOS PLANES DE ACCION DEL GOBIERNO**

##### **Patrocinadores:**

- ☐ La Junta de Planificación para Personas con Trastornos de Desarrollo Físico y Mental del Estado de Nueva York
- ☐ Oficina de Salud para Niños y Adolescentes del Departamento de Salud del Estado de Nueva York, "Socios para la Salud"

##### **Participantes:**

El programa ha sido elaborado para 50 personas de familias con hijos que necesitan una atención médica especial, con particular énfasis en las familias de diversas culturas. A fin de que el mayor número posible de comunidades del Estado de Nueva York esté representado en el proyecto, sólo podrá participar una persona por familia.

**Finalidad:** Capacitar a las familias con hijos que necesitan una atención médica especial para que puedan participar en la elaboración de los planes de acción del gobierno.

##### **Objetivos:**

- ☐ Crear una red de familias con hijos que tienen impedimentos físicos o enfermedades crónicas.
- ☐ Capacitar a los miembros de la red para abogar por los niños y adolescentes que necesitan una atención médica especial y asumir papeles de liderazgo que les permitan influir en la elaboración de los planes de acción que afectan sus vidas.
- ☐ Proporcionar a los participantes información y recursos de comunicación para que se ayuden entre sí.

**Fechas:** Del 3 al 4 de abril y del 1º al 2 de mayo de 1992



- Horario:** Desde las 5.30 p.m. del viernes 3 de abril hasta las 3.30 p.m. del sábado 4 de abril y desde las 5.30 p.m. del viernes 1º de mayo hasta las 3.30 p.m. del sábado 2 de mayo
- Lugar:** Albany, Nueva York
- Costo:** Se reembolsará a los participantes los gastos de viaje, alojamiento, comida y cuidado de sus hijos.

### **Características Generales del Programa "Socios para la Elaboración de Planes de Acción"**

El programa ofrece la información más actualizada sobre los problemas relacionados con los niños que necesitan una atención médica especial y tiene por objeto capacitar a los participantes para abogar más eficientemente por dichos niños y participar en la elaboración de los planes de acción del gobierno.

Para fines de capacitación, se dará un significado amplio al término "miembros de la familia", pudiendo también tratarse de padres con hijos adoptados temporal o definitivamente o de otros miembros de la familia.

### **Definición del término "Niños que necesitan una atención médica especial":**

El punto central del programa de capacitación serán los niños y adolescentes menores de 21 años con impedimentos físicos o enfermedades crónicas que interfieren en gran medida en su crecimiento y desarrollo normales. Algunas de las enfermedades crónicas o enfermedades causantes de impedimentos físicos son: el asma, la parálisis cerebral, la fibrosis quística, la diabetes, la epilepsia, los trastornos genéticos, las enfermedades cardíacas y la leucemia. Hay organizaciones que auspician programas de capacitación para niños que tienen únicamente trastornos mentales o trastornos de desarrollo. La información sobre esos programa se proporciona a petición de los interesados.

### **Información complementaria para los participantes:**

Los organizadores de este proyecto tienen particular interés en recibir solicitudes de inscripción de personas que participan en actividades de autoayuda o cooperación mutua para la atención de niños con necesidades de salud especiales. Se invita a los líderes de grupo a llenar sus solicitudes de inscripción juntamente con los miembros de las redes de apoyo. De esa manera, se creará un grupo de trabajo apropiado para las actividades que los participantes realizarán en sus respectivas comunidades. La realización de actividades de autoayuda o de cooperación mutua no es un requisito indispensable para participar en este programa. Invitamos a presentar solicitudes de inscripción a todas las personas que tengan interés en adquirir mayores conocimientos para abogar por los niños y adolescentes que necesitan una atención médica especial, en conocer el proceso de adopción de leyes, en aprender a dialogar con los líderes de la comunidad y en aplicar esos conocimientos para participar en la elaboración de planes de acción.

### **Requisitos:**

Los participantes deberán comprometerse a asistir a las dos sesiones completas, a cumplir con las tareas que deberán realizar en el lapso que separa a las dos sesiones y a trabajar a nivel local utilizando los conocimientos que han adquirido.



**Servicios de traducción:**

Para facilitar la participación de familias de diversas culturas, los organizadores del programa harán todo lo posible por ofrecer servicios de interpretación simultánea durante las sesiones. A este fin, los participantes deberán indicar en el formulario de inscripción que necesitan los servicios de un intérprete.

Si desea más información, diríjase a:

Mary Huber  
"Partners in Health"  
New York State Department of Health  
Corning Tower, Room 208  
Albany, N.Y. 12237

Teléfono: 518-474-6781  
Fax: 518-473-8673



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza

Albany, New York 12237

Lorna McBarnette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

## SOCIOS PARA LA ELABORACION DE PLANES DE ACCION Formulario de Solicitud de Inscripción

Fecha límite para echar la solicitud al correo: 10 de febrero de 1992

Devuelva a:

Mary Huber  
Partners in Health  
New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208 Corning Tower Building  
Empire State Plaza  
Albany, NY 12237-0618  
(518) 474-6781

Nombre y apellido: \_\_\_\_\_

Dirección: \_\_\_\_\_

Teléfono: ( ) \_\_\_\_\_ Durante el día: ( ) \_\_\_\_\_

1. ¿Tiene usted un/a hijo/a que necesita una atención médica especial? (Le rogamos indicar si tiene más de un/a hijo/a que necesite una atención médica especial. Lea la definición de "Niños que necesitan una atención médica especial" en la hoja adjunta).

☐ Sí ☐ No \_\_\_\_\_ Edad

En caso afirmativo,

- a. Describa el tipo de atención médica especial que su hijo/a necesita y cómo interfiere en su crecimiento y desarrollo normales.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- b. ¿Qué servicios (instrucción escolar, relevos para los padres, coordinación de tratamientos médicos, etc.) recibe su hijo/a actualmente?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Indique qué grado de instrucción tiene su hijo/a: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. ¿Tiene usted otros hijos?

☐ Sí ☐ No

a. En caso afirmativo, ¿cuántos? \_\_\_\_\_

b. ¿De qué edad? \_\_\_\_\_

3. ¿Por qué tiene usted interés en participar en el programa "Socios para la Elaboración de Planes de Acción"? ¿Tiene usted algún problema o preocupación específicos por los cuales quiere inscribirse en este programa?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. ¿Puede comprometerse a asistir dos días seguidos (viernes y sábado), tanto en abril como en mayo de 1992?

☐ Sí ☐ No

5. ¿Tiene que hacer un viaje para asistir a las dos sesiones que se llevarán a cabo en Albany?

☐ Sí ☐ No

En caso afirmativo, indique qué medio de transporte piensa utilizar para venir a Albany: \_\_\_\_\_

6. ¿Necesita algún servicio especial para poder participar en este programa?

☐ Sí ☐ No

En caso afirmativo, indique qué servicio necesita (medios de transporte, intérprete, persona para que cuide a sus hijos, etc.):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. ¿Participa usted en alguna organización que aboga por los niños y adolescentes que necesitan una atención médica especial o desarrolla alguna actividad de autoayuda/ cooperación mutua para dichos niños? En caso afirmativo, indique el nombre de las organizaciones y el papel que usted desempeña.

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Si conoce a alguna persona que realiza actividades de autoayuda/ cooperación mutua o es miembro de las organizaciones arriba indicadas y ha presentado su solicitud de inscripción en este programa, le rogamos que indique los nombres y apellidos a continuación:

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8. Le rogamos tomar nota: La respuesta a este punto es opcional:

Marque la casilla que corresponda:

- |                                 |                                      |                                           |
|---------------------------------|--------------------------------------|-------------------------------------------|
| <input type="checkbox"/> Negro  | <input type="checkbox"/> Hispano     | <input type="checkbox"/> Nativo americano |
| <input type="checkbox"/> Blanco | <input type="checkbox"/> Otras razas |                                           |

9. Díganos algo de usted y su familia.

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10. ¿Ha participado usted alguna vez en el Programa para Niños con Impedimentos Físicos de su condado?

- ☐ Sí                      ☐ No                      Proporcione más detalles:

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11. Díganos cómo se enteró de la realización del Programa de Socios para la Elaboración de Planes de Acción:

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Si desea hacer alguna pregunta sobre el programa, diríjase a Mary Huber.



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Lorna McBarnette  
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH  
Sue Kelly  
Executive Deputy Director

## FACT SHEET

### PARTNERS IN POLICY MAKING:

#### TRAINING FAMILIES OF CHILDREN WITH SPECIAL HEALTH NEEDS TO BECOME ADVOCATES IN INFLUENCING PUBLIC POLICY

#### Co-sponsors:

- ☐ New York State Developmental Disabilities Planning Council
- ☐ New York State Department of Health, Bureau of Child and Adolescent Health, "Partners in Health"

#### Participants:

The program is for 50 individuals from families who have children with special health needs, with particular emphasis on culturally diverse families. In order to accommodate as many regions of the state as possible, participation is limited to one member from each family.

**Goal:** To involve and empower families caring for children with special health needs in policy making.

#### Objectives:

- ☐ To develop a network of families who have children with physical disabilities or who are chronically ill.
- ☐ To provide network members with advocacy and leadership skills that will enable them to effectively influence policy decisions that affect their lives.
- ☐ To provide participants with information and communication resources that will assist them in being supportive to each other.

**Dates:** April 3 and 4, and May 1 and 2, 1992



**Time:** Friday, April 3 from 5:30 pm to Saturday, April 4 at 3:30 pm and Friday, May 1 from 5:30 pm to Saturday, May 2 at 3:30 pm.

**Place:** Albany, New York

**Cost:** Participants will be reimbursed for expenses such as travel, lodging, meals, and child care.

### **Partners in Policy Making: Overview**

The program provides state-of-the-art knowledge about issues related to children with special health needs and enables participants to develop skills to become effective advocates in influencing public policy.

For purposes of this training, families are defined broadly. They can be foster, adoptive, or extended family members.

### **Definition of Children with Special Health Needs:**

The focus of the training is children and youth, under age 21, who have physically disabling conditions or chronic illnesses that interfere significantly with their normal growth and development. Some examples of physically disabling conditions or chronic illnesses are: asthma, cerebral palsy, cystic fibrosis, diabetes, epilepsy, genetic disorders, heart disease, and leukemia. Training programs for children whose only problem is mental illness or developmental disability are available under the auspices of other organizations. Information regarding these programs is available upon request.

### **Additional Information for Participants:**

Conference organizers are particularly interested in receiving applications from those who participate in self-help/mutual support activities for children with special health needs. Facilitators are encouraged to apply along with several members of the support network. This will create a natural working group for activities that participants carry out within their local communities. Participation in self-help/mutual support is not a requirement for participation. Anyone who has an interest in learning more about advocacy skills, the legislative process, how to talk to community leaders, and would

like to apply this information to effect policy changes is encouraged to send in an application.

**Requirements for Participation:**

Participants must agree to participate in both sessions in their entirety, to fulfill tasks that must be completed between sessions, and to translate acquired skills into action at the local level.

**Translation Services:**

In order to encourage the participation of culturally diverse families, conference organizers will make every effort to provide simultaneous translation services during the training. Applicants should note the need for such services on the registration form.

**For additional information, contact:**

Mary Huber  
"Partners in Health"  
New York State Department of Health  
Corning Tower, Room 208  
Albany, NY 12237

Phone: 518-474-6781  
Fax: 518-473-8673



# STATE OF NEW YORK DEPARTMENT OF HEALTH

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Sue Kelly  
Executive Deputy Director

## PARTNERS IN POLICY MAKING Application For Participation

### Application Deadline:

Application must be postmarked by: **February 10, 1992**

### Return to:

Mary Huber  
Partners in Health  
New York State Department of Health  
Bureau of Child and Adolescent Health  
Room 208 Corning Tower Building  
Empire State Plaza  
Albany, NY 12237-0618  
(518) 474-6781

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: (\_\_\_\_) \_\_\_\_\_ Daytime Number: (\_\_\_\_) \_\_\_\_\_

1. Are you a parent of a son or daughter with a special health need? (Please indicate if you have more than one child with a special health need. See attachment for definition of "special health need.")

☐ Yes ☐ No \_\_\_\_\_ Age

If yes,

- a. Describe the special health need and how it interferes with your child's normal growth and development.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- b. What services (school, respite care, case management, etc.) is your son/daughter currently receiving?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Describe the school placement: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. Do you have other children?

☐ Yes ☐ No

a. If yes, how many? \_\_\_\_\_

b. What ages? \_\_\_\_\_

3. Why are you interested in participating in the Partners in Policy Making project?  
Is there a specific issue, area of concern, or problem that encourages you to apply  
for this program?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. Will you make a time commitment of two days (Friday and Saturday) during the months  
of April and May 1992?

☐ Yes ☐ No

5. Will you travel to Albany to attend the two meetings?

☐ Yes ☐ No

If yes, please indicate how you will come to Albany: \_\_\_\_\_

6. Are there any special accommodations necessary for you to participate in this program?

☐ Yes ☐ No

If yes, please describe (accessibility, interpreters, child care, etc.):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. Do you participate in any advocacy organizations or self-help/mutual support  
activities for children with special health needs? If so, please list and describe your role.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If you know of other participants from the above organizations or activities who are submitting applications for this training session, please list their names below.

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8. Please note: completion of this question is optional:

Check category that applies:

- ☐ Black    ☐ Hispanic    ☐ Native American  
☐ White    ☐ Other

9. Please tell us a little about yourself and your family.

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10. Have you ever participated in your county's Physically Handicapped Children's Program?

☐ Yes    ☐ No    Please explain below:

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11. Please indicate how you learned about the Partners in Policy Making project:

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Inquires about this program can be directed to Mary Huber.

STATE OF NEW YORK  
DEPARTMENT OF HEALTH

**DOH**  
NEWS

FOR RELEASE: IMMEDIATE  
Friday, January 24, 1992

PARTNERS IN POLICY MAKING TRAINING PROGRAM

ALBANY, January 24 -- The New York State Health Department and the State Developmental Disabilities Planning Council are seeking members of families with children who have special health needs to participate in a four-day "Partners in Policy Making" training program to be held in Albany, on April 3-4 and May 1-2, 1992.

The training program will provide current information about issues related to children with special health needs, and will assist participants to develop the skills needed to become effective advocates in influencing the public policy decisions that affect their lives.

Registration for the program is limited to 50 participants, so only one person per family will be accepted. Participants must come from families which include a child or youth, under age 21, who is physically disabled or has a chronic illness. These conditions or illnesses include, but are not limited to: asthma, cerebral palsy, cystic fibrosis, epilepsy, genetic disorders, heart disease and leukemia. There is no cost to participants. The program sponsors will pay for lodging and meals during the sessions, and will reimburse for other related expenses, such as travel and child care.

The deadline for applications is February 10, 1992. For more information and application forms, contact: Mary Huber, Partners in Health, Bureau of Child and Adolescent Health, N.Y.S. Health Department, 208 Corning Tower, Albany, NY 12237-0618; or, call (518) 474-6781.

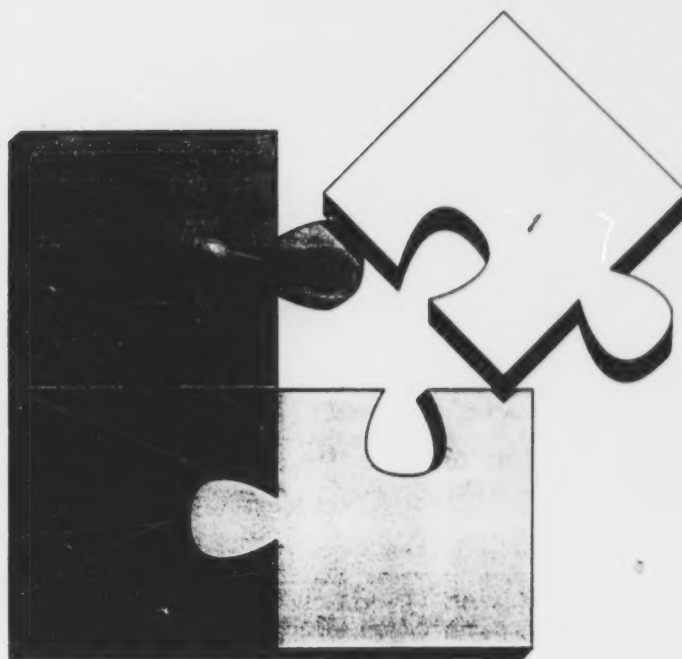
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# **Partners in Health Promotes Parent to Parent Support Networks**

*Child Link, Fall 1992*



New York State Department of Health  
Bureau of Child and Adolescent Health

## Partners in Health Promotes Parent-to-Parent Support Networks,

by Mary Huber

**N**ew York State has long been rich in the cultural diversity of its families. Today, according to the 1990 census, 31 percent of those 21 or younger are racially and ethnically diverse. Based on a prevalence rate of one or two percent of children who have severe chronic illness, there may be 18,000 to 36,000 culturally diverse children who have special health needs in New York State (NYS).

Chronic disabilities present many challenges and stresses to all families, especially families who are culturally diverse. Problems of language, cultural patterns of interaction, and general disenfranchisement from society's resources may create additional barriers to providing care for their children.

It is the premise of the Special Projects of Regional and National Significance (SPRANS) grant, *Partners in Health (PIH)*, that culturally diverse families of children with special health needs can be strengthened and empowered to cope if they participate in self-help/mutual support. First and foremost, self-help/mutual support ends the isolation that so often affects those going through difficult times. A group of peers experiencing the same thing provides camaraderie and one of the most basic human needs—connections to others.

This sense of connectedness fosters communication and mutual support and provides the setting for providing practical information and problem solving. Often, as participants recognize common problems, they join forces as

advocates for changing the institutional and societal structures that may impede progress. As a result, those who share a common concern are no longer people with a problem; they are helpers, and the number of helpers in the community increases dramatically.

Although many culturally diverse groups have a strong self-help/mutual support tradition, we soon realized that few culturally diverse families who have children with disabilities were engaged in self-help/mutual support, or as it is more commonly identified within the children with special health care needs arena, parent-to-parent support. Barriers include families' lack of information regarding the potential benefits of support networks and a lack of incentives for existing groups to retain families long enough for them to find out about these benefits. Professionals who have the potential to inform families about parent-to-parent support are not themselves convinced of its usefulness and do not spread the word. In some instances, families have found that existing parent groups do not respect cultural diversity. Often groups are not geographically accessible. For some, concrete help is much more important than sharing feelings. PIH attempted to address these barriers through local and statewide activities. Statewide activities will be discussed first.

### Statewide Activities

PIH was designed to build on existing parent-to-parent networks and to expand their availability to

culturally diverse families. However, the project found that there was no systematic compilation of such resources, and neither professionals nor parents could connect to them except within limited geographic areas. In addition, many children with special health needs have rare disorders for which it is impossible to link families within the same community. Connections across the state can be made by phone only if families know whom to call.

With these needs in mind, PIH contracted with a self-help clearinghouse to develop a statewide directory. Particular attention was given to the New York City area, which is most likely to have a significant number of parent networks for culturally diverse families.

A second major statewide activity was the sponsorship of the parent training program, *Partners in Policymaking*. Conceived by the Developmental Disabilities Planning Council (DDPC) in Minnesota, *Partners in Policymaking* is a national model of leadership training for people with disabilities, parents and family members. As such, it is a perfect vehicle for implementing PIH's goals of empowering culturally diverse families to care for their children.

While the NYS DDPC had offered the program previously, it had no mechanism for targeting families who have children with special health needs. It also wanted to increase the number of culturally diverse families who participated. Staff made a particular effort to reach those groups.



## Reaches Culturally Diverse Families Via Media, Friends, Health Units

### Partners in Health, from page 6

With data gathered through the directory, it distributed applications to all parent-to-parent networks statewide as well as Native American health clinics, foster parent organizations and agencies serving culturally diverse families. A press release went to media that had major population centers of culturally diverse families. Local health units distributed information to families they knew. While the announcement did not exclude anyone, it also emphasized that culturally diverse families were particularly welcome. Newspapers, friends, and local health department programs for children with special health needs attracted the most families.

The program reduced financial barriers by reimbursing for all expenses, including travel, lodging and child care. But other barriers may persist. Although child care is reimbursed, only 20 percent of the applicants were single parents, perhaps because child care is not available at any cost. Some families cannot afford to pay the expenses up front. In some instances, local organizations provided stipends so families would not have to wait for reimbursement.

Of the 150 applicants, 141 identified their ethnocultural background. Of that number, 30 were black, 12 Native American, 8 Hispanic, and 1 Asian American. The need for concrete information, especially as it relates to financial concerns, was apparent in the application. In partnership with Developmental Disabilities Planning Council and the state's Title V Children with Special Health

Needs Program, PIH designed an agenda that combined presentation on issues related to children with special health needs; small group work that encouraged parents to recognize their strengths and develop action plans; and skill development that would assist them in influencing policy. We found it crucial to include overnight stays, since it was in the leisurely times outside the formal program that parents developed ongoing relationships.

### Statewide Outcomes

There were several important outcomes. The NYS Department of Health, which operates the Title V Children with Special Health Care Needs Program, now has a cadre of parents who have offered to participate in other initiatives. They have practiced speaking before groups and know that their opinions are important. Subsequently, parents have been panelists in training for professionals on the importance of parent-to-parent networks. They have participated in training professionals on cultural competency and are eager to participate in future activities.

Partners in Policymaking also provided a mechanism for identifying culturally diverse parents who were already involved in parent-to-parent networks and could serve as mentors to others interested in doing the same. In addition, tips for existing groups that would enable them to provide help in a manner that is consonant with the cultural patterns of families were presented for everyone's consideration. These included holding meetings in locations accessible and comfort-

able for all families; contacting indigenous community leaders to encourage participation; and advertising in media utilized by culturally diverse families.

Although a formal evaluation of outcomes of participants has not yet occurred, anecdotal information is positive. For example, a Native American mother applied to become a member of the NYS DDPC. She also envisions a day when there will be a Special Olympics for Native American children. A mother whose child has sickle cell disease is being more assertive with her child's physician. Others are helping to create local forums for parent empowerment.

### Local Activities

At the local level, PIH has been addressing the barriers to involvement in parent-to-parent support by building a culturally competent partnership between two relevant elements of the service delivery system: 1) case management programs for children with special health care needs and their families, which are operated by county health units as part of the state's Title V Children with Special Health Care Needs programs, and 2) community-based self-help clearinghouses. The purpose of case management is to coordinate a wide range of services and programs families may find useful in caring for their children. This includes referral to and development of parent-to-parent networks. Self-help clearinghouses specialize in linking families to informal supports, such as other families

Partners in Health, continued pg. 8



## Numbers Listed for Self-Help Clearinghouses

**T**he American Self-Help Clearinghouse has compiled these phone numbers for use in finding or forming a mutual aid self-help group. States marked with an asterisk (\*) maintain listings of additional local clearinghouses operating within the state. The 1-800 numbers in parentheses are for making calls from within the state. Numbers marked with two asterisks (\*\*) indicate that only information on groups is available from that number.

### States

California (310) 825-1799 (1-800-222 LINK)  
 Connecticut (203) 789-7645  
 Illinois\* (708) 328-0470 Administrative (708) 328-0471  
 Iowa (515) 576-5870 (1-800-383-4777)  
 Kansas (316) 689-3843 (1-800-445-0116)  
 Massachusetts (413) 545-2313  
 Michigan\* (517) 484-7373 (1-800-777-5556)  
 Minnesota (612) 224-1133\*\*  
 Missouri  
   Kansas City (816) 472-HELP  
   St Louis (314) 773-1399  
 Nebraska (402) 476-9668  
 New Jersey (201) 625-9565 (1-800-FOR-MASH)  
 New York  
   Brooklyn (718) 875-1420  
   Upstate (914) 949-6301\*\*  
 North Carolina  
   Mecklenberg area (704) 331-9500  
 Ohio  
   Dayton area (513) 225-3004  
 Oregon  
   Portland area (503) 222-5555\*\*  
 Pennsylvania  
   Pittsburgh area (412) 261-5363  
   Scranton area (717) 961-1234  
 South Carolina  
   Midlands area (803) 791-9227  
 Tennessee  
   Knoxville area (615) 584-6736  
   Memphis area (901) 323-0633  
 Texas\* (512) 454-3706  
 Washington DC area (703) 941-LINK  
**National U.S. Listings and Directories**  
 American Self-Help Clearinghouse (201) 625-7101, TDD 625-9053  
 National Self-Help Clearinghouse (212) 642-2944  
**Other U. S. Resources**  
 National Organization for Rare Disorders (1-800-999-NORD)  
 Alliance of Genetic Support Groups (genetic illnesses) (1-800-336-GENE)  
 National Clearinghouse for Infants with Disabilities and Life-Threatening Conditions (1-800-922-9234).

### Partners in Health, from page 7

who are caring for children with special needs. Activities have taken place in four county demonstration sites where both programs existed prior to the grant.

One of the goals of the project was to develop culturally competent self-help clearinghouses. To that end, the three clearinghouses hired culturally diverse staff, one of whom is also the parent of a child with special health needs. This has proven to be especially advantageous. Outreach can occur through the regular activities that take place in the course of caring for a child, whether that be meeting other parents who are bringing their children to summer camp, distributing flyers or putting up posters in the waiting area when her daughter has an appointment, or meeting other caregivers at school.

In addition to enhancing parent-to-parent networks for all chronically ill children and their families, clearinghouses have also made a special effort to engage culturally diverse families. This involved a multi-pronged approach based upon the principles and methods of community organizing, that is: learning about the culturally diverse community; developing relationships with key persons in the community so they can maintain ownership of the process; and marketing parent-to-parent networks to key groups. Some of the results of this effort are highlighted below.

### Local Outcomes

In Albany, the State Department of Health's Genetics Services Program introduced staff to a parent whose child has sickle cell disease. She had participated in a





### **Partners in Health, from page 8**

sickle cell support group, but it had dissolved, and she was interested in starting it anew. The self-help clearinghouse provided organizational resources so she could start her own group.

In Long Island, the clearinghouse became aware that a major hospital which serves 125 families whose children have sickle cell disease had no support group. Through a collaborative effort, a group is now in place.

In Niagara County, the clearinghouse noted the success of the Partners in Policymaking in attracting parents to conferences that offered skill development. It organized a training program designed to assist parents in helping themselves and others through the maze of health and education systems. Mileage

**Partners in Health, to page 11**

### **Information Sources**

For information on self-help clearinghouses in your area and for additional information on **Partners in Health**, contact: Mary Huber, Director **Partners in Health: Self-Help/Mutual Support for Culturally Diverse Children with Special Health Needs and Their Families**, New York State Department of Health, Corning Tower, Room 208, Albany, NY 12237, (518) 474-6781

For information on State Developmental Disabilities Planning Councils, contact: Dave Hancox, Director, **Partners in Policymaking**, Minnesota Planning Council on Developmental Disabilities, Box 24, 1313 5th Street, S.E., Minneapolis, MN 55414, (612) 349-2559.

### **'92 Projects, from page 1**

*Project Special Care*, a project of the Indiana Parent Information Network, Inc.—in collaboration with the Marion County Step Ahead Council, the Indiana Program for Children with Special Health Care Needs, and others—will develop a comprehensive system of child care for children with severe disabilities and medically complex health needs in Marion County. The project will identify and recruit family home day care providers, before and after school programs, and child care centers; research and develop a curriculum for in-service training of child care providers; adapt existing materials for accessing and evaluating child care programs to meet the needs of families of children with special needs; provide support to 25 or more severely handicapped or chronically ill children and their families in varied child care settings; and research costs incurred for child care of children with very special needs. Project Director: Donna Gore Olsen, Indianapolis, IN (317) 257-8683.

*Washington State Children's Community Health Access Project*, is a project of the Grays Harbor County Health Department. This project focuses on four rural counties with large percentages of Native Americans and Mexican Americans, disproportionately high rates of poverty, teen age pregnancies, and children with developmental disabilities, and a lack of appropriately trained and local health care providers. The Departments of Health in these counties, the University of Washington, and Seattle Pacific University are collaborating to provide a model, comprehensive, coordi-

nated health care delivery system for rural children with special health care needs and their families that include family and tribal centered care; local assistance to tertiary medical specialists to provide ethno-culturally sensitive consultations; and interaction among health care providers, educators, consultants, and families within the community to provide effective and comprehensive medical and developmental assessments and realistic management plans. Project Director: Stella Lamoreaux, R.N., P.H.N., Aberdeen, WA (206) 532-8631.

*Child Care Plus*, a child care system for children with special health care needs is a project of the Fairfax (Virginia) County Office for Children. The county, in collaboration with the Association for Retarded Citizens of Northern Virginia, will develop and expand child care services for children with special health care needs within a comprehensive, family-centered system. The project will focus on three functional areas: recruitment of child care providers interested in caring for children with special health care needs and families whose children need such child care providers; provision of comprehensive and culturally-competent training and technical assistance to care providers; and coordination of services so that all involved in the care of a given child (parents, child care providers, medical professionals, community agencies) will know the outcome objectives for the child and will coordinate their efforts to develop these objectives. Project Director: Roberta Owens, Fairfax, VA (703) 218-3740.



## Products and Publications

*There is a Future.* Duke University Medical Center. Videotape of teenagers talking frankly about coping with chronic illness. Purchase \$35, rental \$20. Inquiries to Julia Gaskel, Duke University Medical Center, Box 2916, Durham, NC 27710. (919) 684-3401.

*The Self-Help Sourcebook: A National Guide to Finding & Forming Mutual Aid Self-Help Groups.* 4th Ed., 1992. Described by *The Woman's Newspaper* as "An invaluable resource for the individual, the family, and the professional or anybody who is looking for support from a group. . . [Its price] is about the equivalent of 25 fruitless phone calls and 40 miles of wasted driving." Available from the American Self-Help Clearinghouse, Attn: Sourcebook, St. Clares-Riverside Medical Center, Denville, NJ 07834. Include check payable to St. Clares-Riverside Medical Center, prices for U.S. delivery are \$10 first class, or \$9 book rate.

*How to Develop a Community Network: A Guide for Those Seeking to Improve Services for Children with Special Health Care Needs.* Pathfinder Resources, 2nd Ed., 1992. Guidelines to assist parents and/or health and human services providers in building networks and in solving problems they may encounter along the way. Includes community resource assessment forms. Available from Pathfinder Resources, Inc., 2324 University Av. W, Suite 105, St. Paul, MN 55114. (612) 647-6905. Price \$9.95, includes mailing.

*Paying the Bills. Tips for Families on Financing Health Care for Children with Special Needs.* 1992. A reader friendly, informative booklet containing such useful information as how to appeal an insurance company's denial of coverage. *Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs, Health Assessment Tools.* 1992. A tool for assessing the degree to which individualized services, health care professionals and

agencies, the local community, and state health departments offer community-based, family-centered care. *Assessing the Adequacy of National Health Care Reform Proposals*, a draft report analyzing three health care reform proposals in relation to such criteria as access, benefits, consumer choice, family coverage, and cost containment. Contact New England SERVE, 191 Tremont Street, Suite 812, Boston, MA 02108. (617) 574-9493.

**Partners in Health**, from page 9 reimbursement and small stipends were made available to all participants. It attracted more parents than all prior efforts to start traditional self-help/mutual support groups.

Partners in Health has learned that culturally diverse families have and will participate in parent-to-parent support. It may vary in form from more traditional mutual support efforts, but the result is the same—greater family control over their own lives and a helping hand offered to others.

Child Link  
Janet Adams ..... Managing Editor

Division of Services for Children with Special Health Needs  
Marie McPherson, M.D. .... Director  
Diana Denboba ..... Public Health Analyst

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Georgianna Larson ..... Executive Director  
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### ARE YOU ON OUR MAILING LIST?

If you would like to receive Child Link or if your address is wrong in any way, we want to know.

Please complete and return to Pathfinder Resources, 2324 University Avenue W, Suite 105, St. Paul, MN 55114, (612) 647-6905, (Fax) 647-6908

\_\_\_\_\_ Please add my name to your mailing list

\_\_\_\_\_ Please correct my name/address

Name \_\_\_\_\_

Title \_\_\_\_\_

Organization \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip \_\_\_\_\_



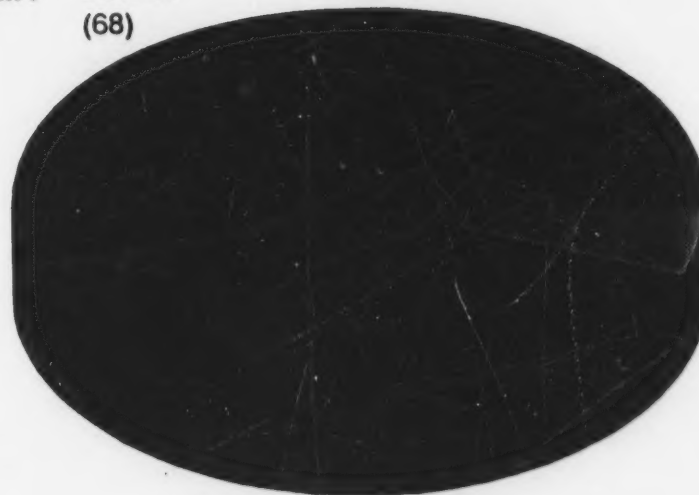
**Presentation Graphics:  
Analysis of Questionnaires  
Completed by Culturally  
Diverse Participants in  
Partners in Policy Making Six  
Months after the Core  
Sessions**



New York State Department of Health  
Bureau of Child and Adolescent Health

# Cultural Diversity of Partners in Policy Making Participants

Caucasian 66.0%  
(68)



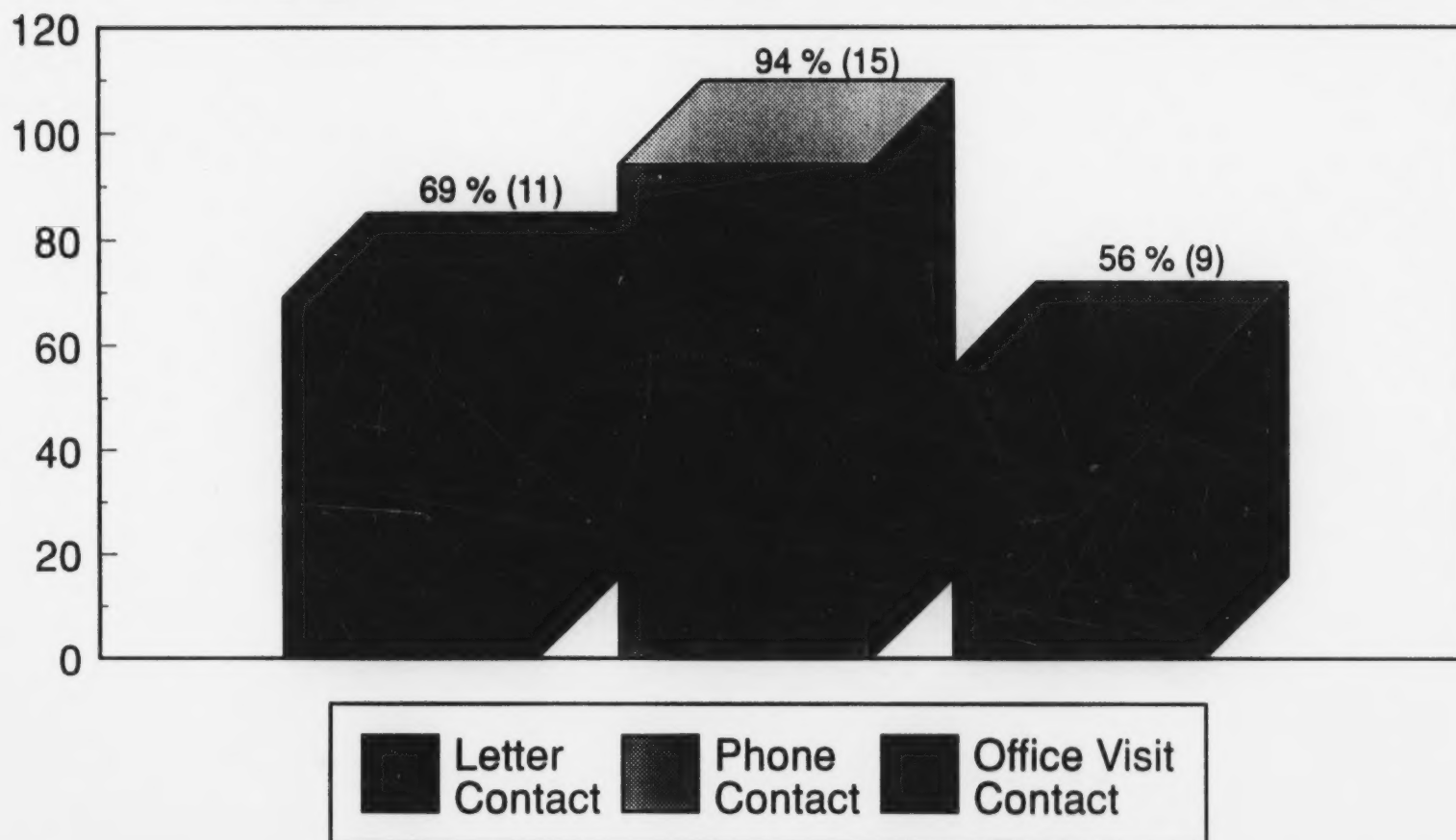
Native American 5.8%  
(6)  
Hispanic 1.9%  
(2)

African American 26.2%  
(27)

103 Total Participants

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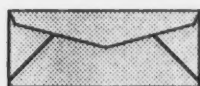
# Type of Contact to Officials



20 African Americans, Hispanics  
and Native Americans

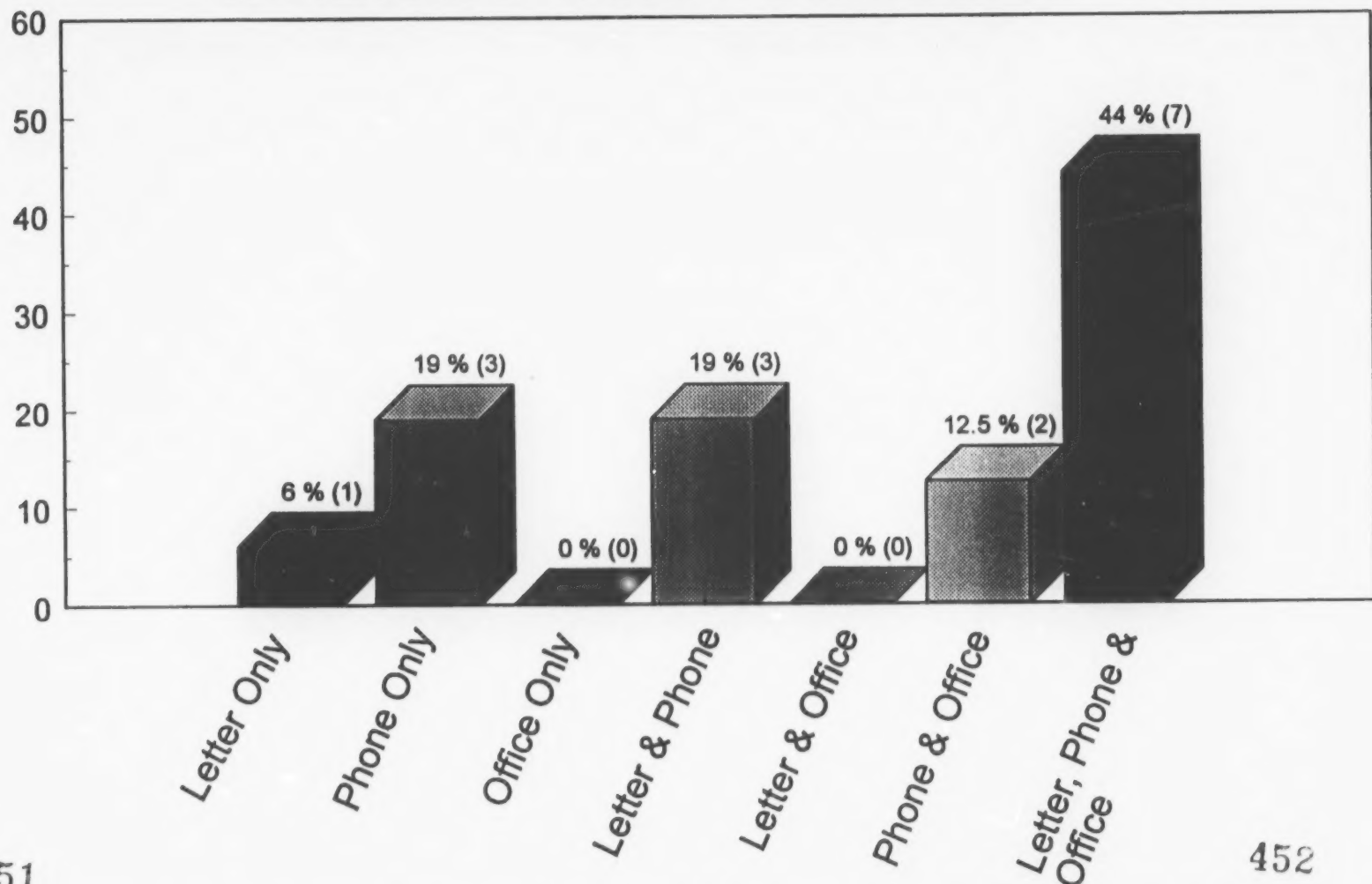
16 of which made Contact

449



450

# Further Breakdown of Type of Contact with Officials

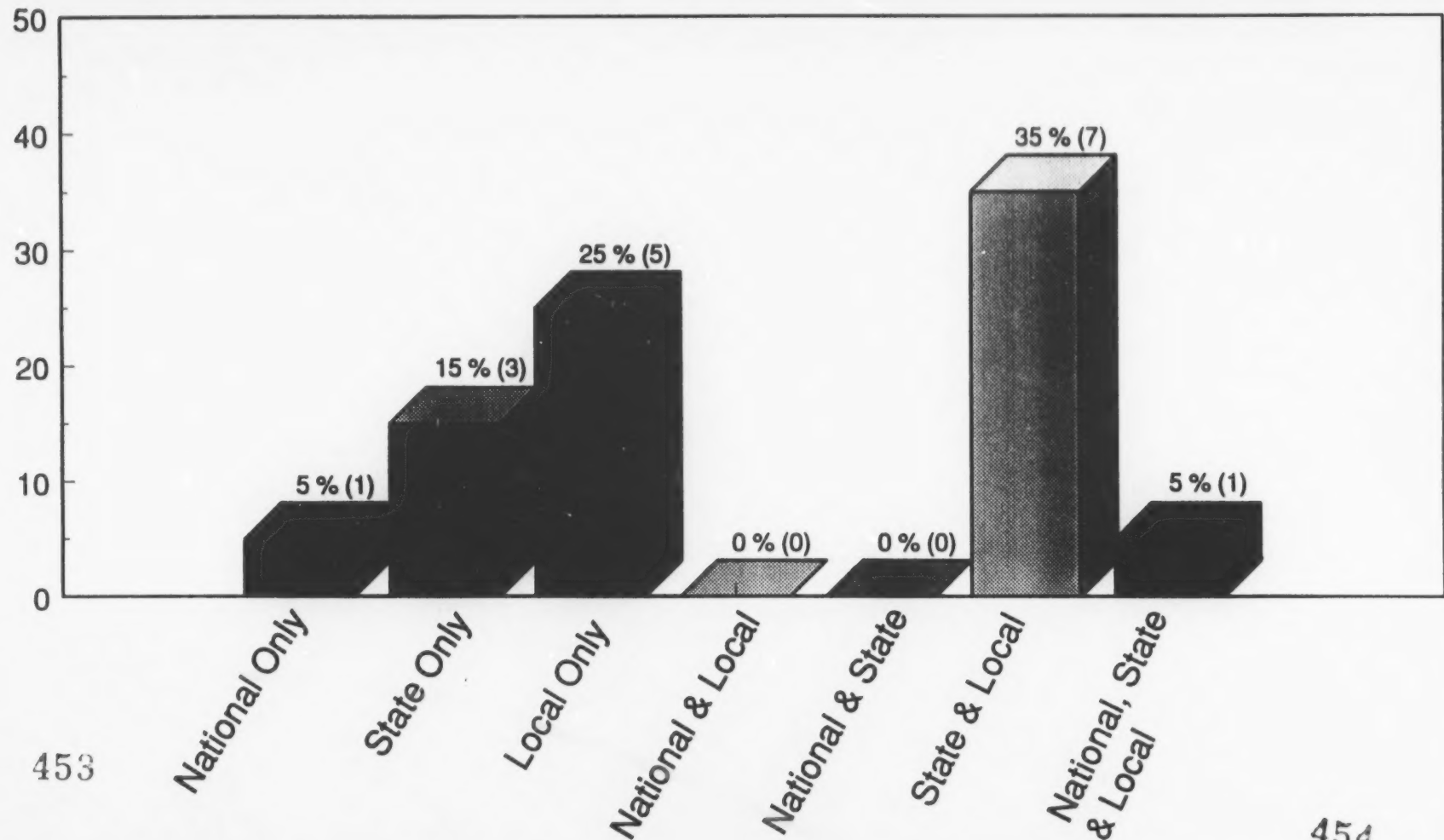


451

452

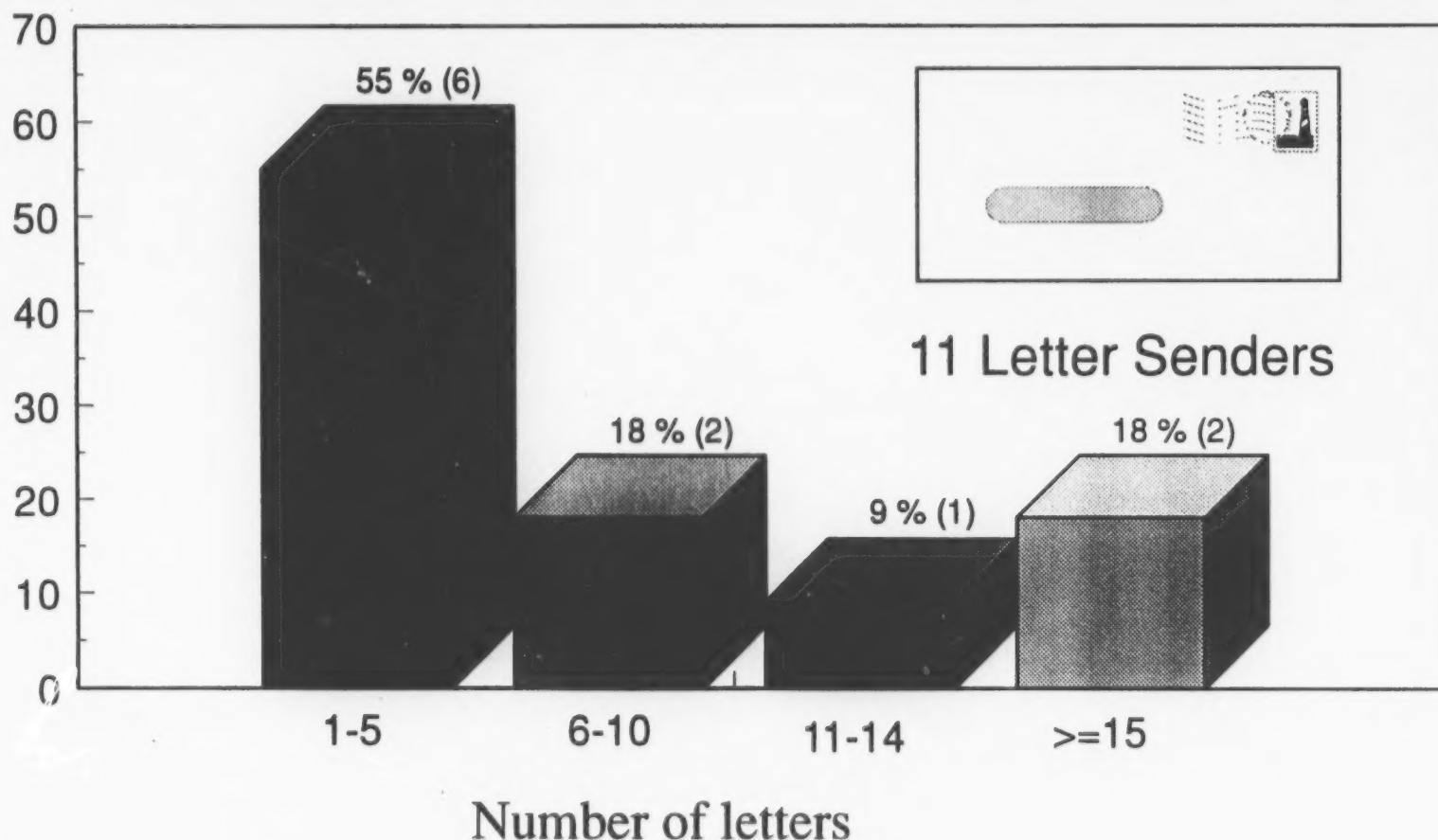
20 African Americans, Hispanics, and Native Americans, 16 Made Contact

# Further Analysis of Contact with National, State and Local Officials



453 20 African Americans, Hispanics and Native Americans 454

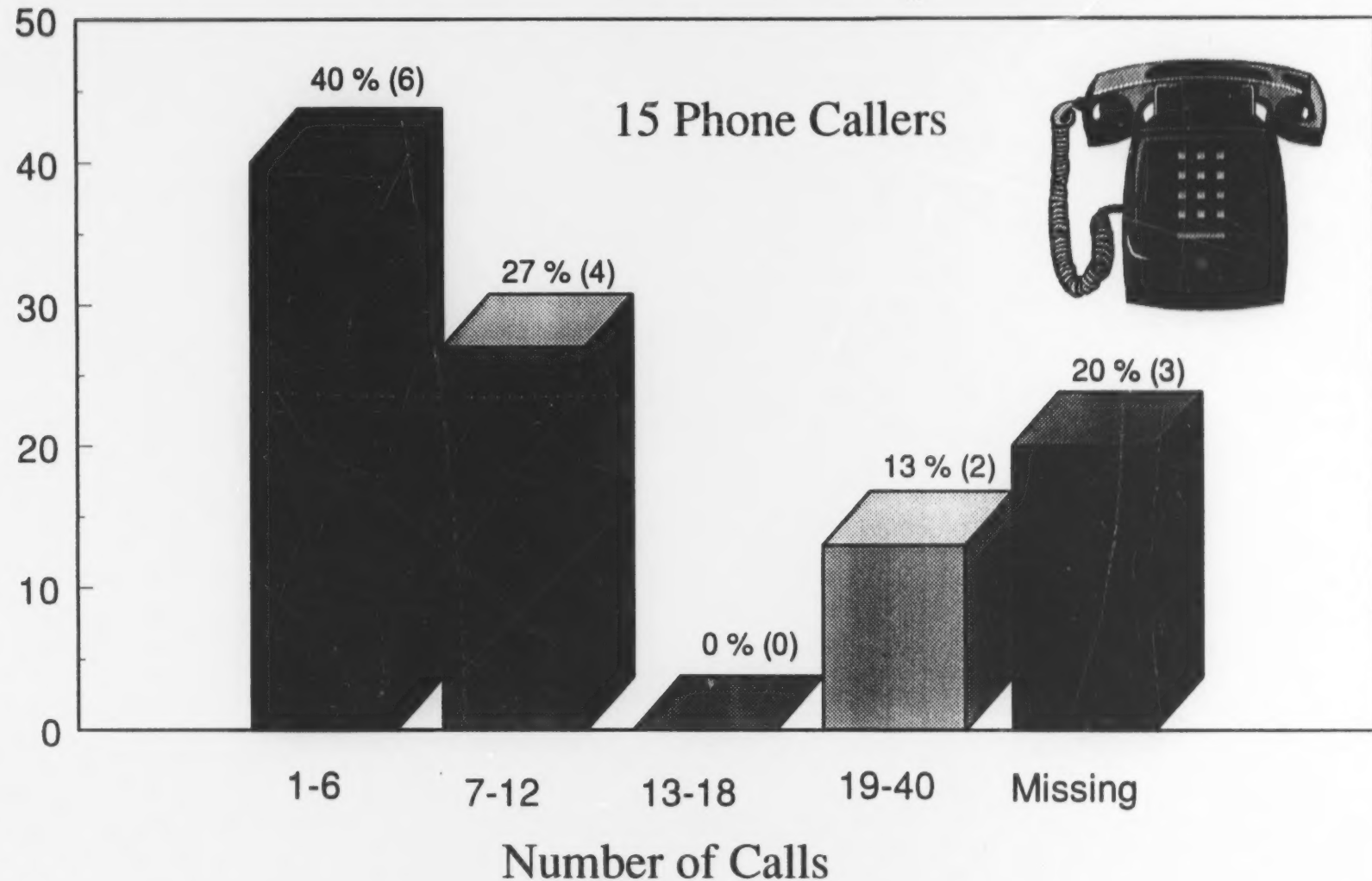
# Analysis of Letter Contact



20 African Americans, Hispanics and Native Americans

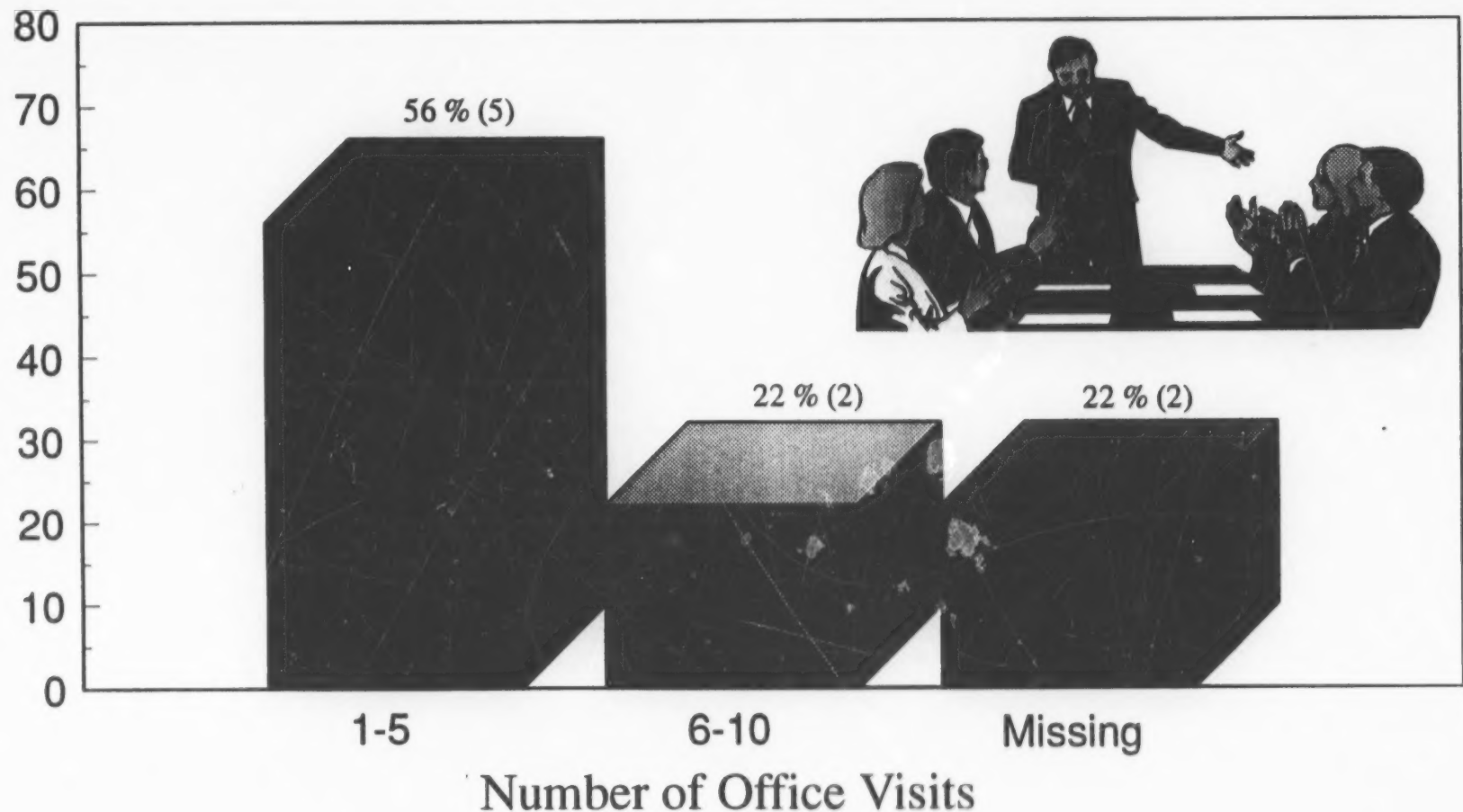


# Analysis of Phone Contact



20 African Americans, Hispanics and Native Americans

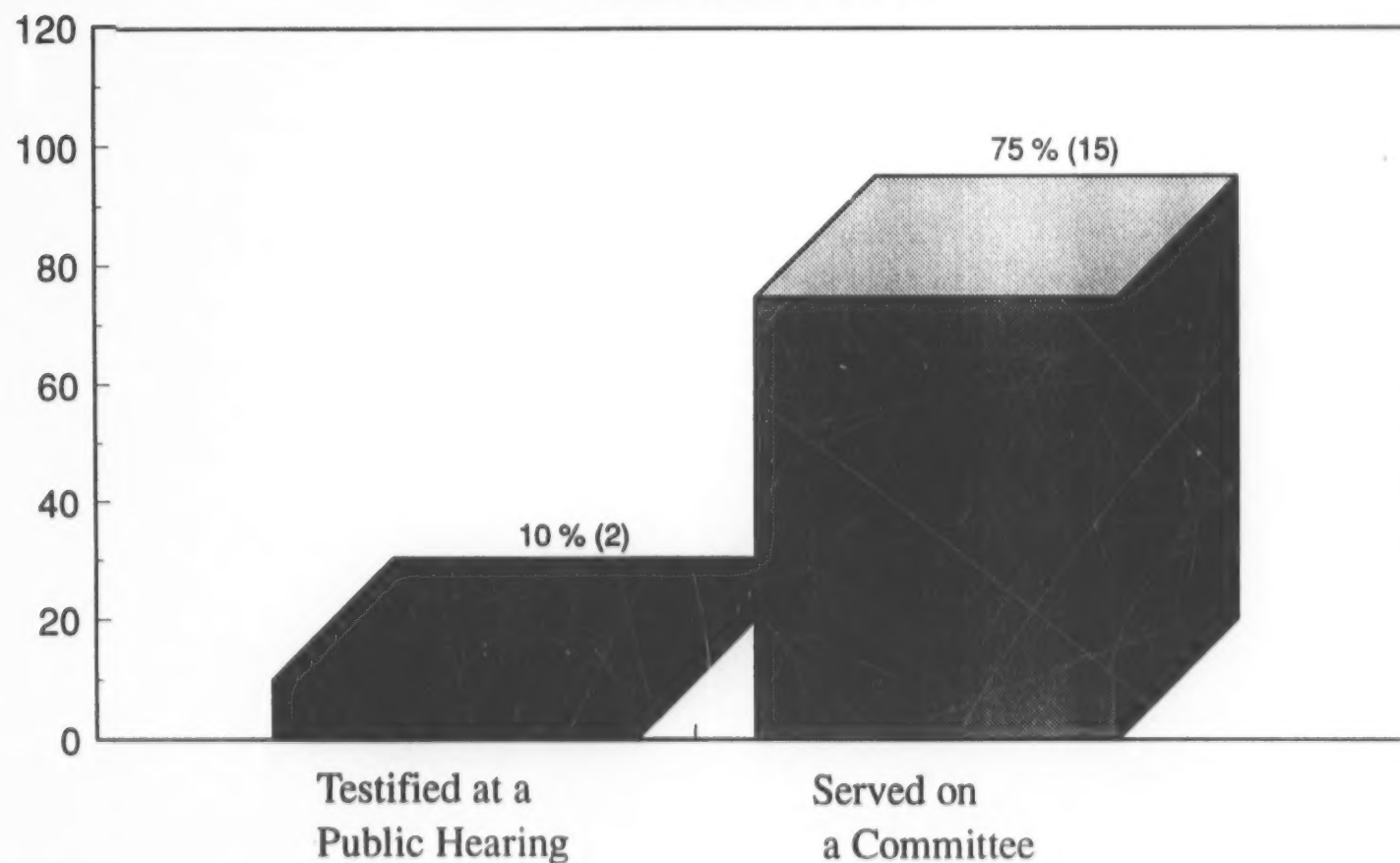
# Analysis of Office Visit Contact



9 Participants Made Visits

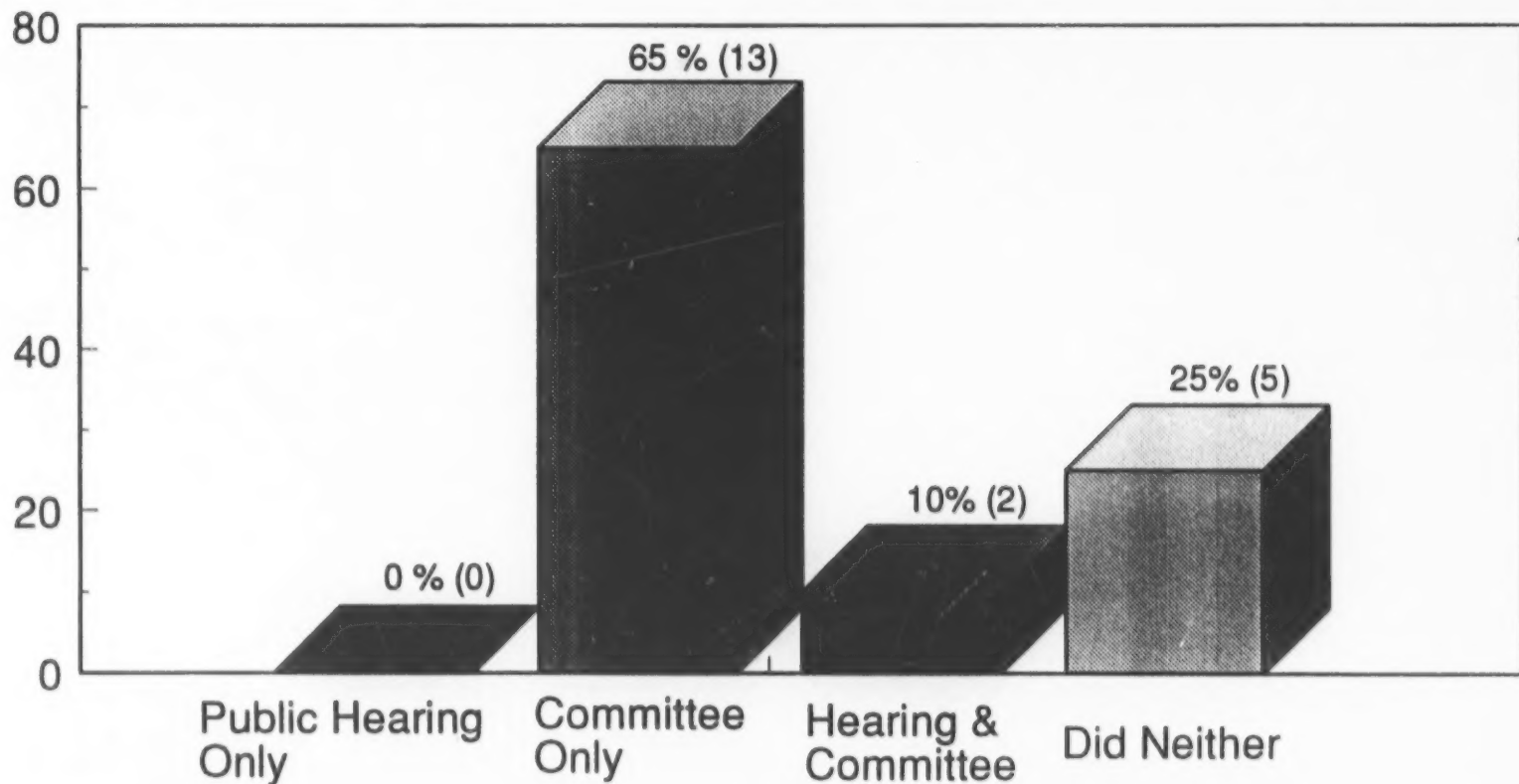
20 African Americans, Hispanics and Native Americans

# Other Avenues of Advocating for Yourself or Other Persons with Disabilities



20 African Americans, Hispanics and Native Americans

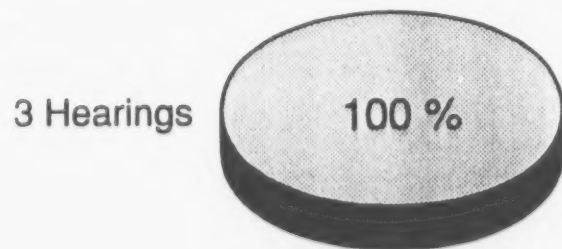
# Analysis of Other Advocacy Opportunities



20 African Americans, Hispanics and Native Americans

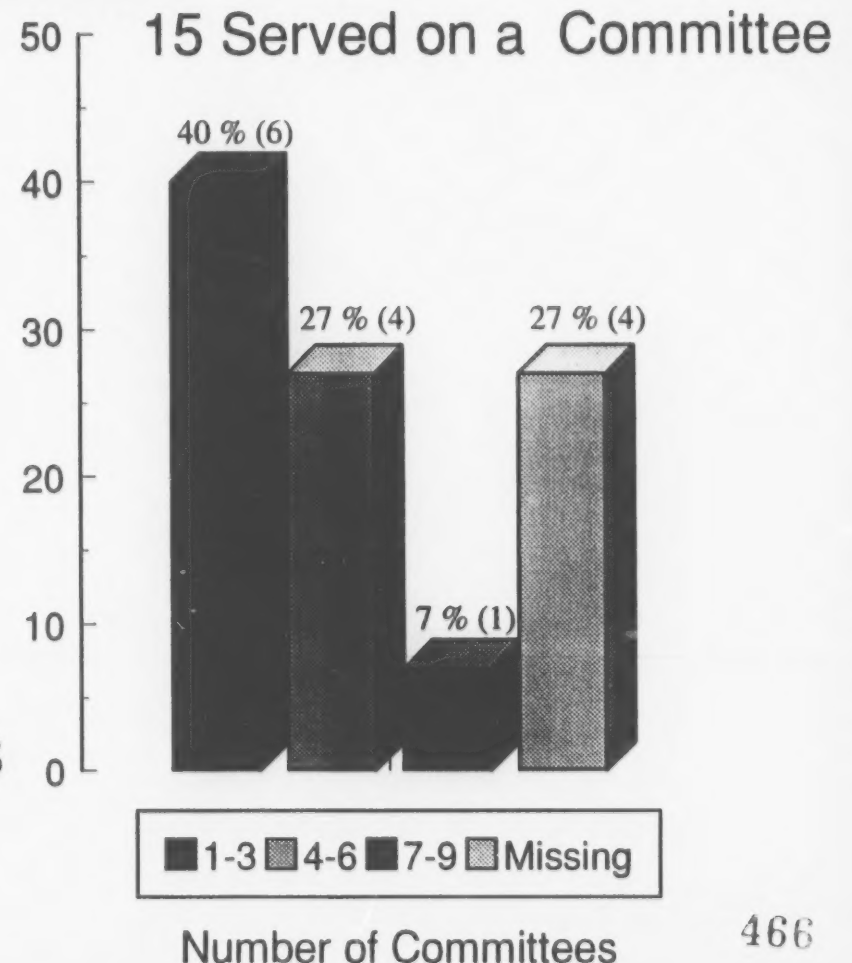
# Analysis of Numbers of Hearings Testified at and Committees Served on

Two People Testified at Three  
Hearings Each



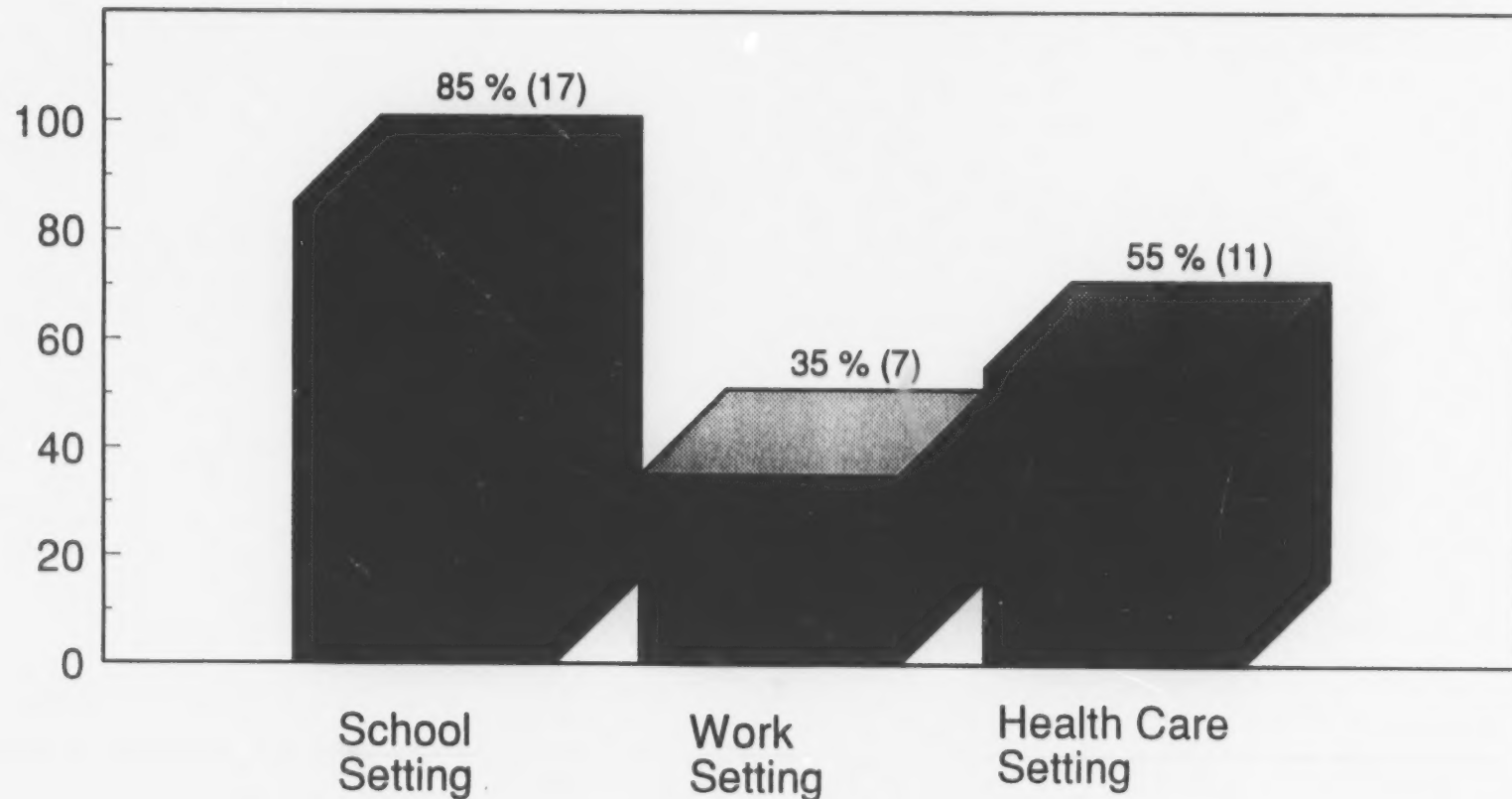
African Americans, Hispanics  
and Native Americans

465



466

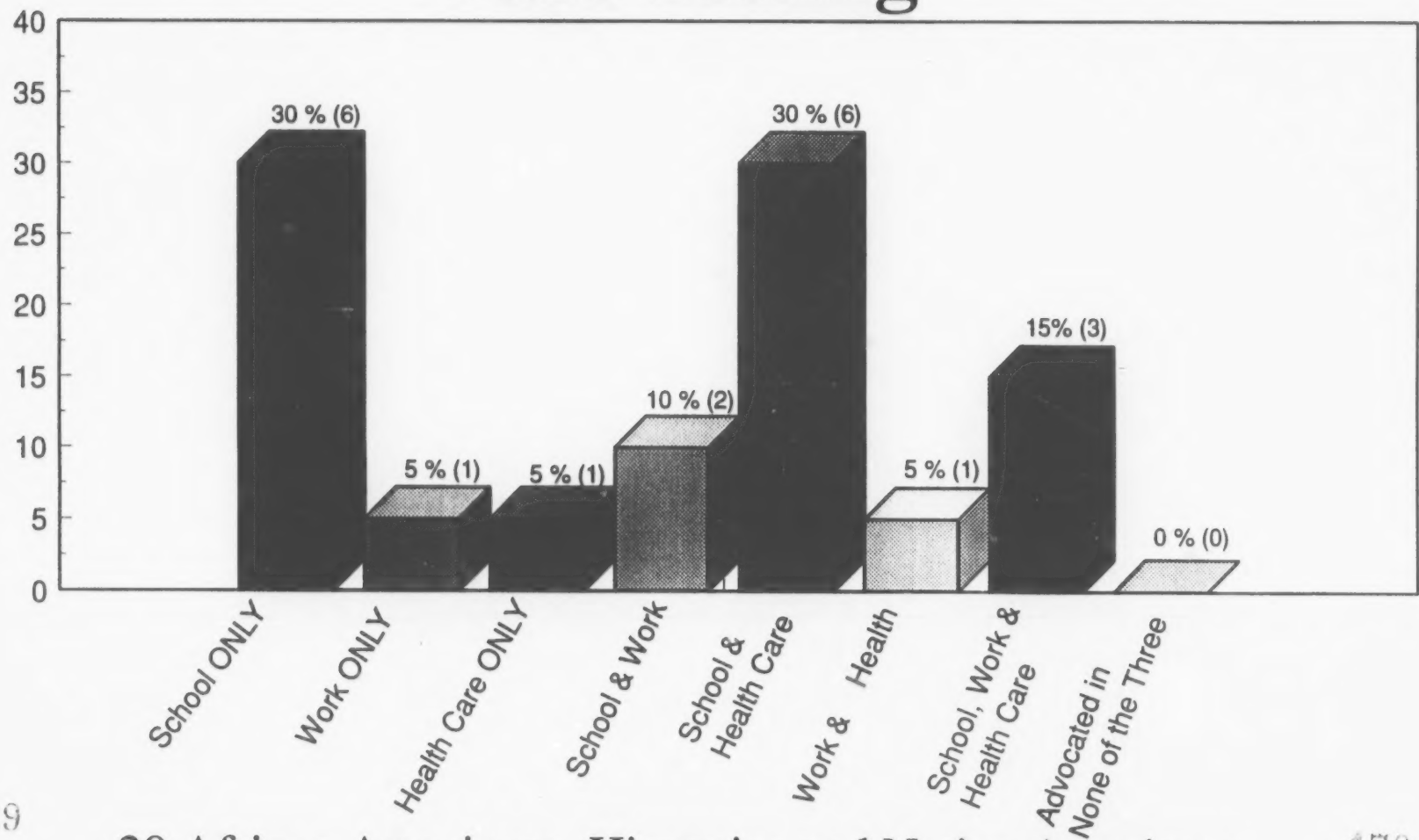
# ● Analysis of Advocacy in School, Work and Health Care Settings ●



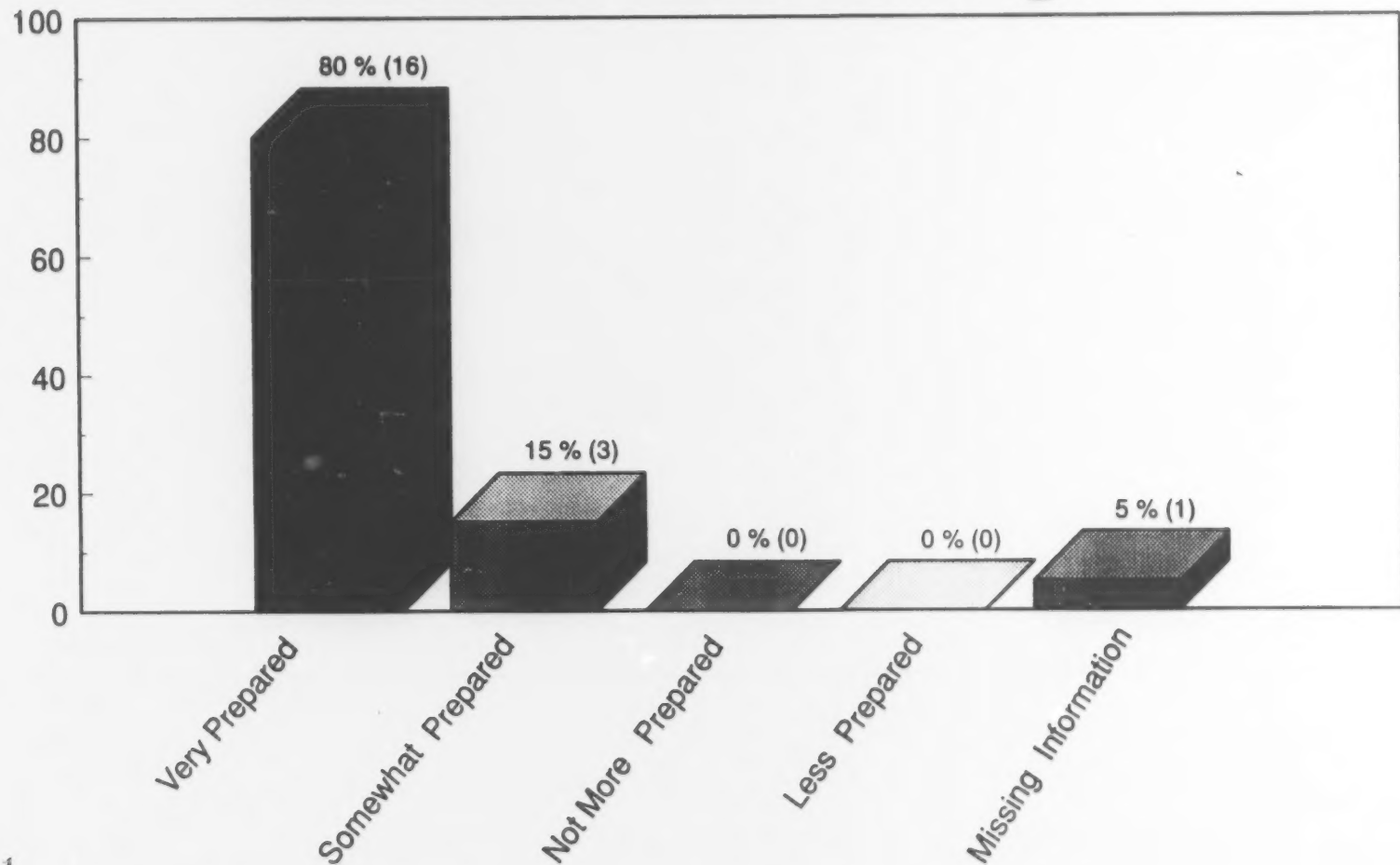
20 African Americans, Hispanics and Native Americans



# Further Analysis of Advocating within a School, Work and Health Care Setting



# Degree of Preperation the Partners Program Provided to Advocate in the School, Work and Health Care Settings

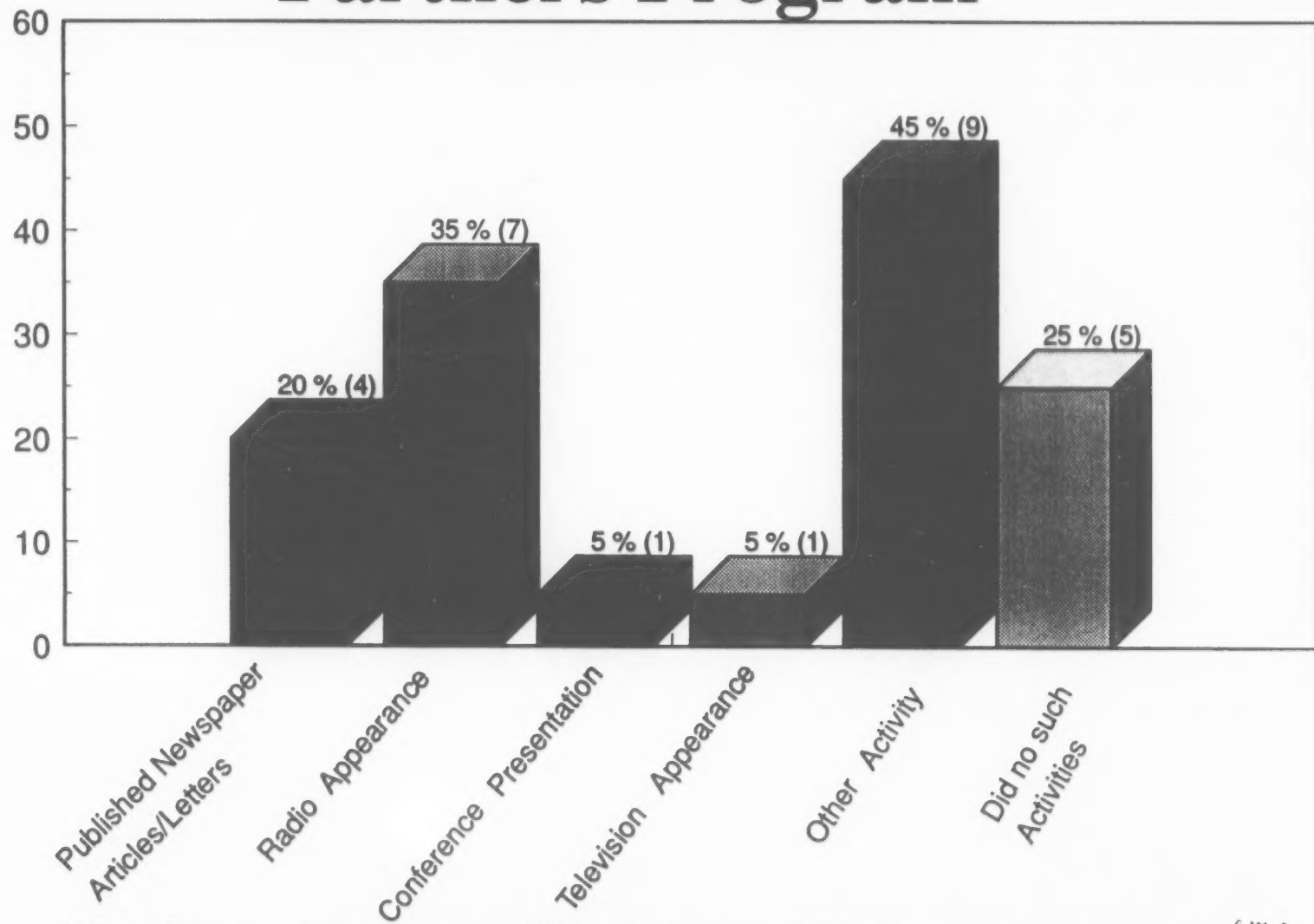


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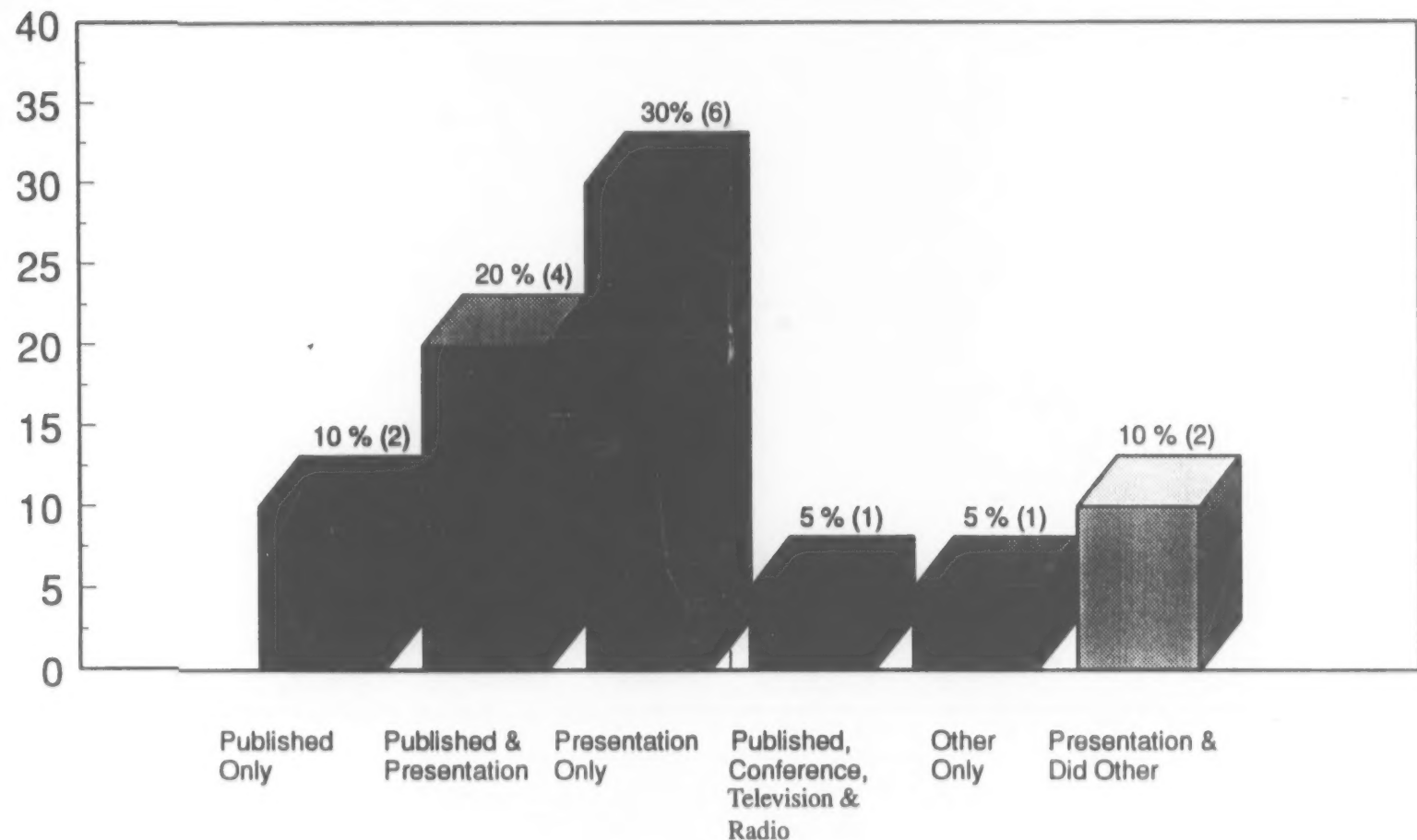
20 African Americans, Hispanics and Native Americans

472

# Public Education Efforts Since the Partners Program

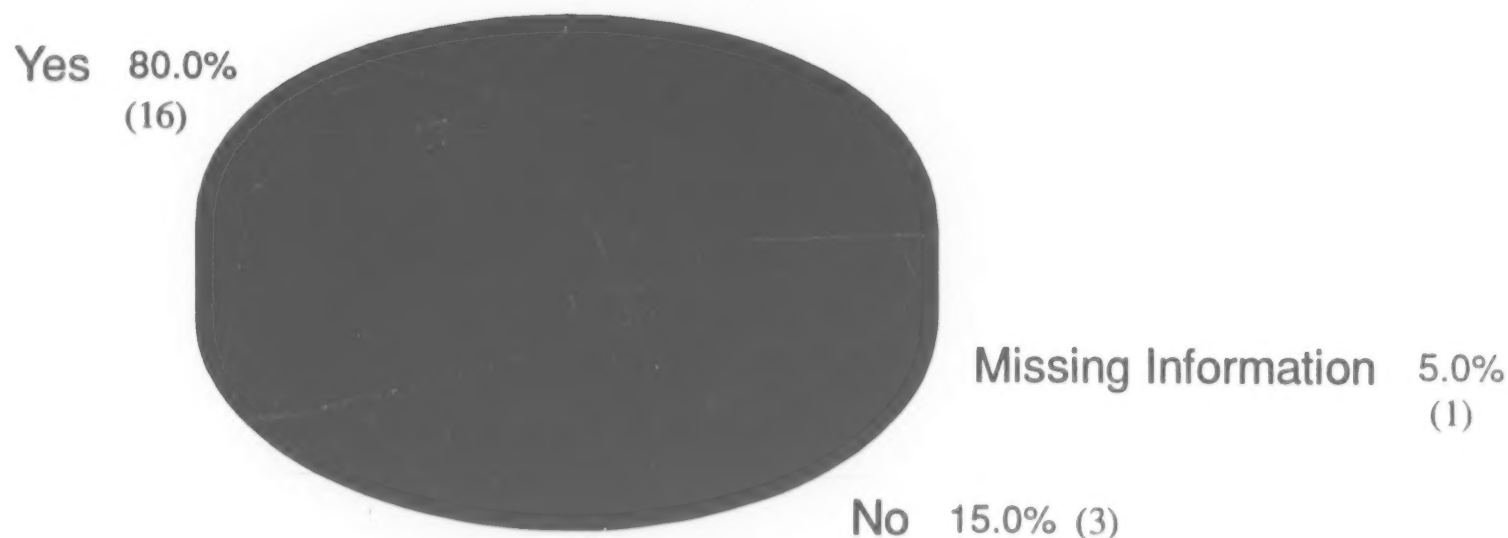


# • Further Analysis of Education Efforts •



20 African Americans, Hispanics and Native Americans

# Analysis of Obtaining More Appropriate Services as a Result of the Partners Program



20 African Americans, Hispanics and Native Americans

# Unrecorded Benefits from the Partners Program

Other Benefits 90.0%  
(18)

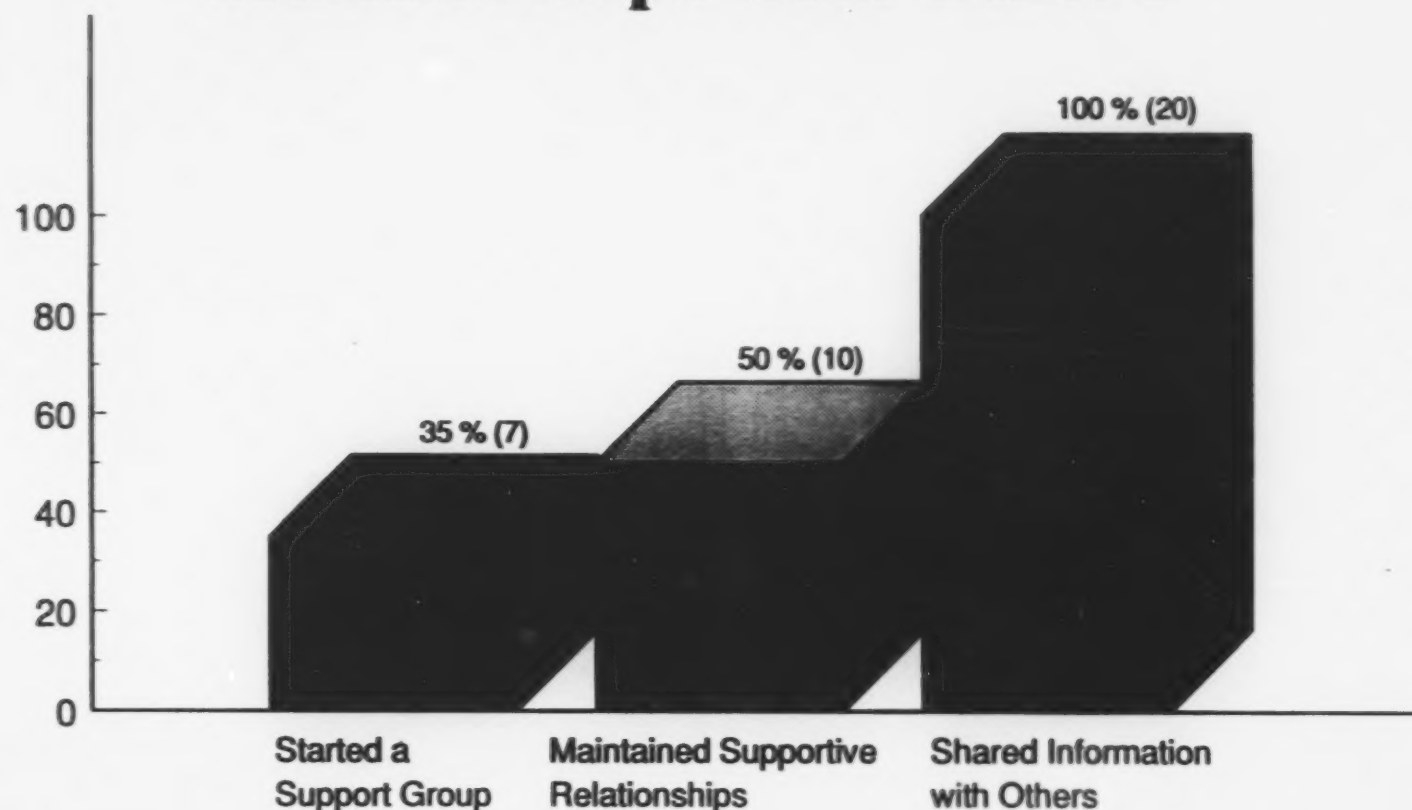


No Other Benefits 10.0%  
(2)

20 African Americans, Hispanics and Native Americans

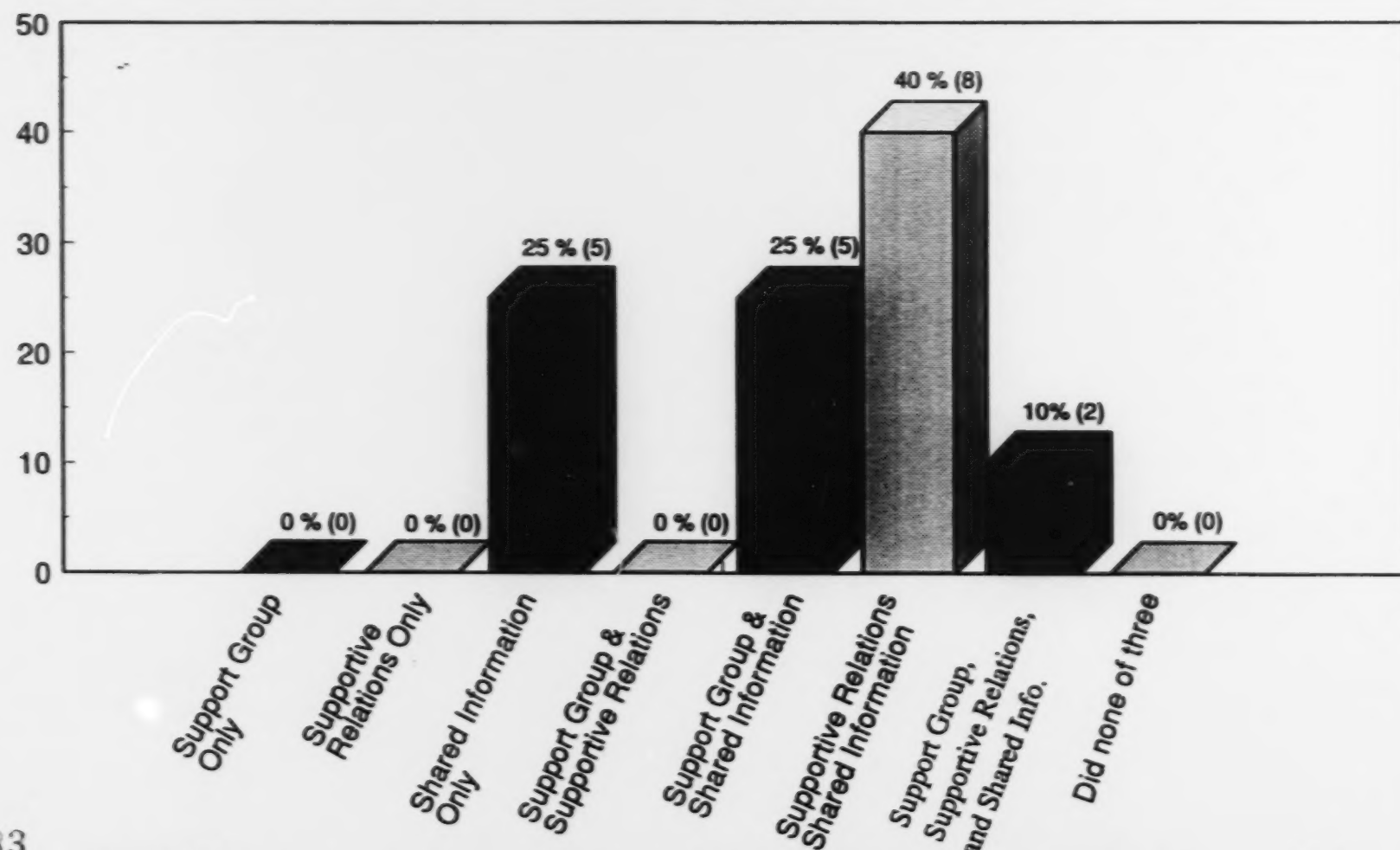


# Analysis of Starting Support Groups, Sharing Information and Maintaining Supportive Relationships with Others

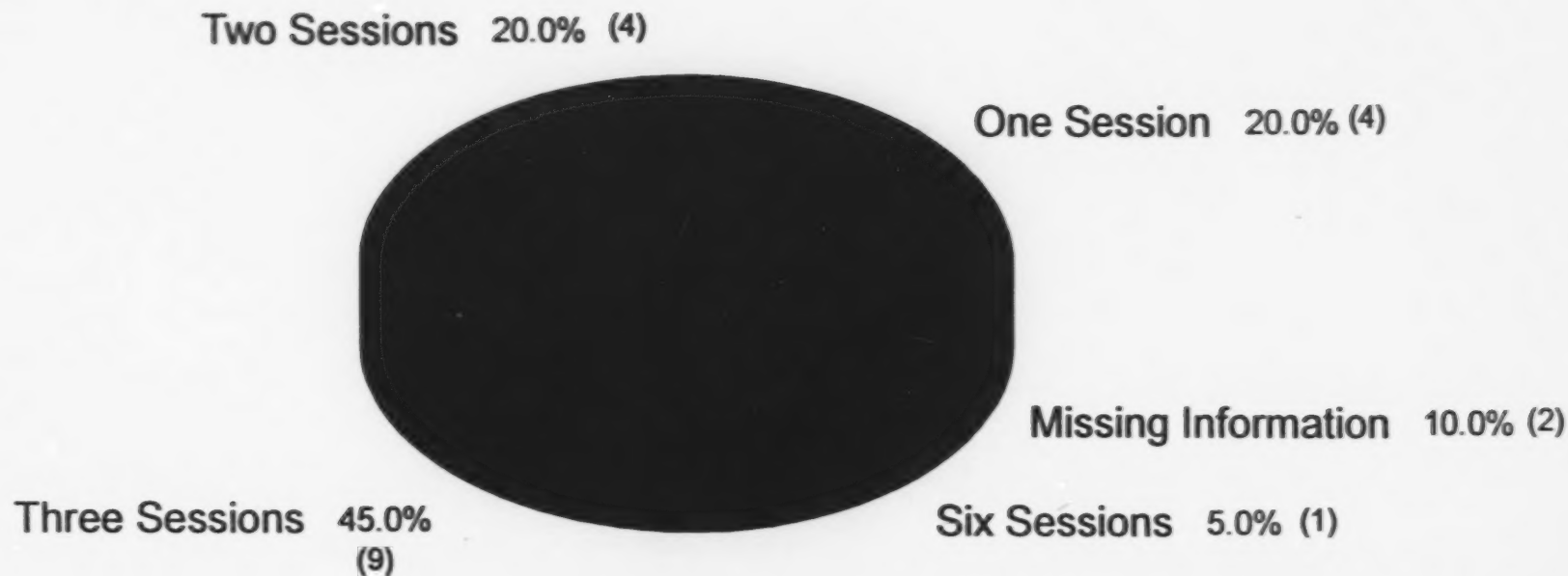


20 African Americans, Hispanics and Native Americans

## Further Analysis of Starting Support Groups, Sharing Information and Maintaining Supportive Relationships with Others



# Number of Sessions Attended\*



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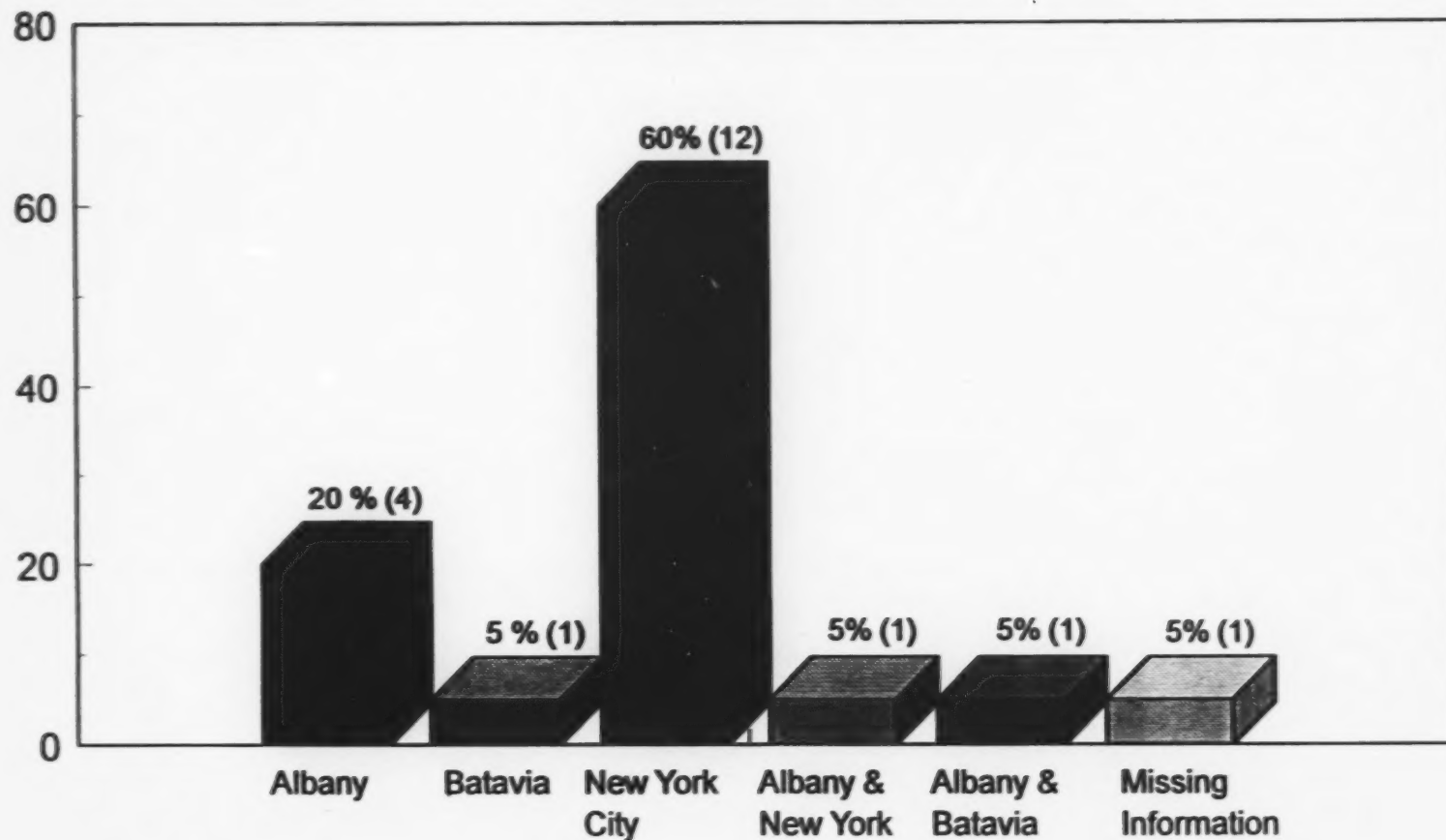
20 African Americans, Hispanics and Native Americans

485

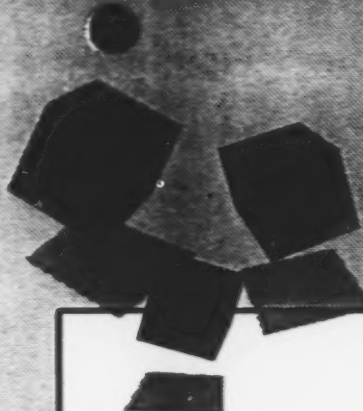
\* One respondent took part in previous trainings under a different program

486

# Location of Partners Program Sessions



20 African Americans, Hispanics and Native Americans



## Comparison of Important Response Rates between Culturally Diverse and Caucasian Respondants

### Culturally Diverse

80 %

Contact with State, Local and  
National Officials

45 %

Made Office Visit Contact

75 %

Testified at a Public Hearing or  
Served on a Committee

100 %

Advocated in a School, Work or  
Health Setting

85 %

Advocated in School Setting

35 %

Advocated in Work Setting

55 %

Advocated in Health Care Setting

### Caucasian

88 %

33 %

55 %

79 %

73 %

18 %

45 %

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## Further Comparison of Important Response Rates between Culturally Diverse and Caucasian Respondants

### Culturally Diverse

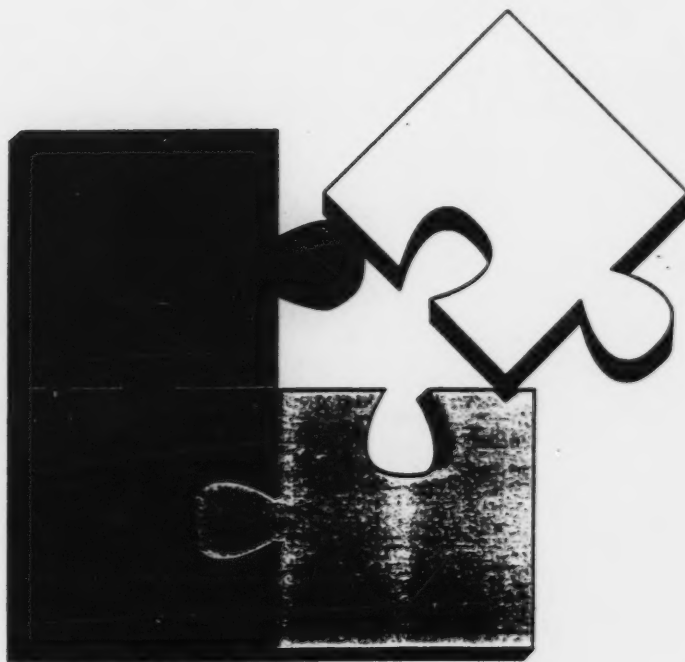
### Caucasian

|       |                                                                                   |      |
|-------|-----------------------------------------------------------------------------------|------|
| 80 %  | Indicated Partners in Policy Making left them Very Prepared to Become an Advocate | 69 % |
| 75 %  | Engaged in Public Education Efforts                                               | 64 % |
| 80 %  | Obtained More Appropriate Services                                                | 63%  |
| 35 %  | Started a Support Group                                                           | 21 % |
| 50 %  | Maintained Supportive Relationships                                               | 39 % |
| 100 % | Shared Information with Others                                                    | 94 % |
| 90 %  | Listed Unrecorded Benefits                                                        | 70 % |

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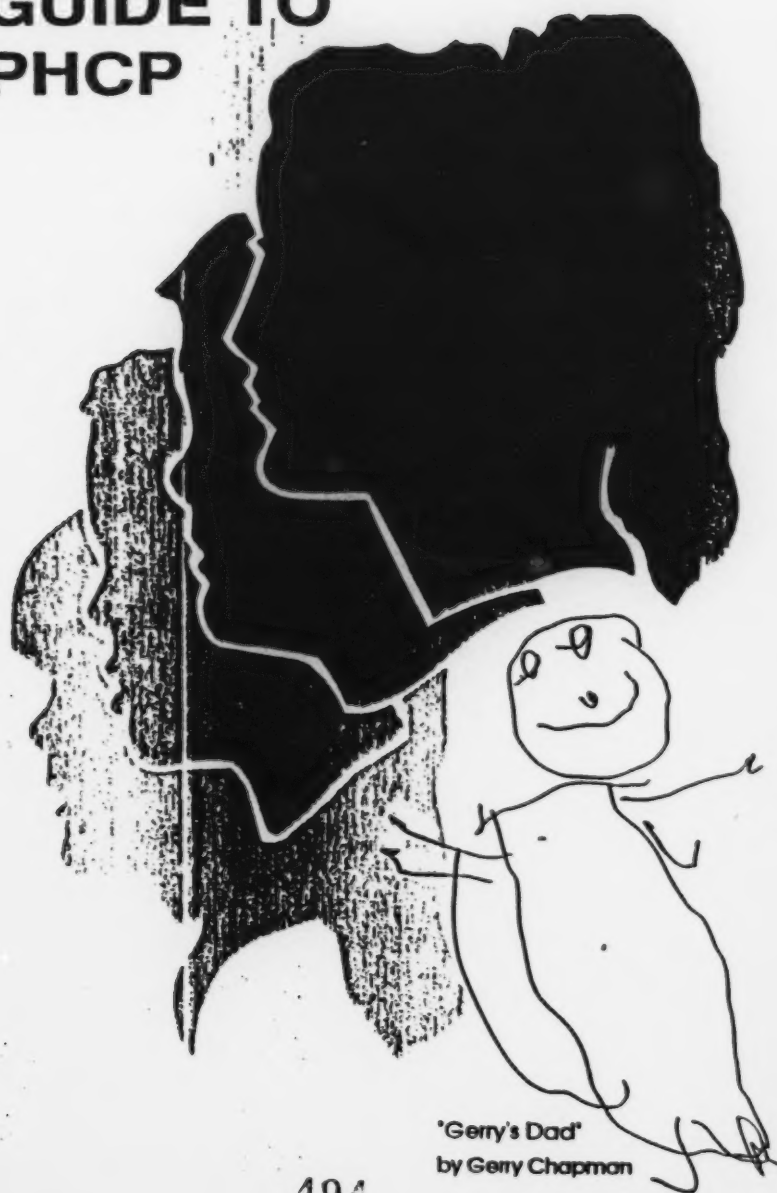


**Correspondence from  
Physically Handicapped  
Children's Program of  
Erie County**



New York State Department of Health  
Bureau of Child and Adolescent Health

# PARENTS GUIDE TO PHCP



'Gerry's Dad'  
by Gerry Chapman

## **PARENT'S GUIDE TO PHCP**

### **I. PROGRAM OVERVIEW**

PHCP is the Physically Handicapped Children's Program (sometimes called "State Aid"). Its purpose is to make high quality medical care available to children who have serious medical or handicapping conditions. To be eligible for this program the child must be a resident of Erie County and be under 21 years of age. Eligibility also depends on the child's medical diagnosis and the family's financial status. Some of the conditions covered by the program are: prematurity, congenital heart defects, cleft palate, cerebral palsy, cystic fibrosis, orthopedic problems, diabetes, blood diseases, childhood cancer, chronic kidney disease, seizure disorders, profound hearing loss, spina bifida, and serious congenital physical defects. PHCP will help pay for medically necessary diagnostic, treatment and rehabilitation services or equipment requested by a New York State approved physician for an eligible child.

### **PRE-AUTHORIZATION/PRIOR APPROVAL**

The program has specific standards of care for various conditions and will not pay for any care which does not meet these standards. In general, diagnosis and treatment must be provided by physicians listed in the Directory of Approved Specialists in New York State. Diagnosis, evaluation and treatment must be provided, at least partially, by a center approved by the special Children's Services Division of the New York State Department of Health. All treatment and services, except for emergencies, must be approved BEFORE the care is provided. Under certain circumstances, PHCP will retroactively approve requests for services that are received in the PHCP office no later than 90 days after care has been delivered.

### **PAYOR OF LAST RESORT**

PHCP is not a substitute for health insurance. PHCP will help pay for authorized services only after all sources of health insurance have been fully utilized.

### **COPAYMENT**

The program operates within a copayment system. Family financial information is reviewed by program staff to determine if a family will be required to copay for services and what the percentage of that copayment would be. After the insurance has paid its share for an approved service, the family pays its percentage of copayment and PHCP pays the rest, up to the State approved Medicaid rate.

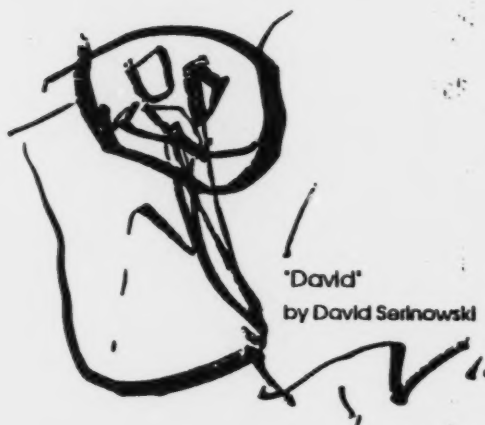
## II. APPLICATION PROCESS

The application process involves several steps:

- a request for services
- general eligibility review
- medical review
- financial review
- the determination

When all the steps have been completed, the program will notify the family of its decision.

### 1. REQUEST FOR SERVICES



A New York State approved specialty physician must apply or request coverage of services for the child.<sup>1</sup> If your child is being seen by more than one specialist or clinic, each must apply for coverage under PHCP. A parent cannot apply. Parents must sign a form that acknowledges the request for services and consents to the sharing of

medical information for their child. The request should be submitted BEFORE care is provided. However, under special circumstances, the Erie County PHCP will process requests that are received no later than 90 days after the care has been delivered. Requests for services delivered prior to this 90 day limit will not be honored.

#### Parent Responsibilities:

- Provide information as requested.
- Sign Parent Acknowledgement and Consent (Blue Form).

#### Provider<sup>2</sup> Responsibilities:

- Fully complete the Recommendation for Medical Services (FORM DOH 696).

<sup>1</sup> In Erie County a parent may, in most cases, request Children's Hospital of Buffalo Patient Accounts Department to initiate the request for services.

<sup>2</sup> Provider is a person or group who supplies medical goods or services pertinent to PHCP. Some examples are specialty physician, clinics, pharmacies, etc.

## **2. GENERAL ELIGIBILITY REVIEW**

The information included in the request for services is screened by program staff to determine if the general information is within the limits of the program. (For example: the child is a resident of Erie County, the child is under 21, the diagnosis is on the currently approved list.)

## **3. MEDICAL REVIEW**

The information submitted by the specialist is reviewed by the PHCP Medical Director to determine:

1. That the child's diagnosis is one covered by PHCP.
2. That services requested are appropriate for the diagnosis.
3. That the services requested are covered by PHCP.
4. That the services will be delivered by a New York State approved provider.

Requests for additional information or medical justification may be sent to the provider. Copies of the request are sent to the parent.



### **Provider Responsibilities:**

- Return additional information or medical justification within 10 days of the request.

### **Parent Responsibilities:**

- Follow up on requests for additional information or medical justification, if necessary.

#### 4. FINANCIAL REVIEW

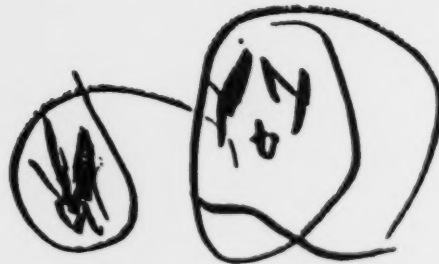
An application form is sent to the family to be completed and returned with income verification and insurance information. This information will be reviewed by PHCP staff to determine if the family's adjusted income falls within the program limits and to set the family's level of copayment. The family will be required to apply for Medicaid if the application indicates that the family may be eligible.

##### PHCP Responsibilities:

- Review financial information.
- Determine financial eligibility.
- Determine the family's level of copayment.

##### Parent Responsibilities:

- Fully complete and return application.
- Enclose COPIES of the previous year's 1040 tax form (including all schedules) and the last 4 pay stubs.
- Provide any other income documentation requested by PHCP.
- Enclose a COPY, front and back, of any insurance cards.
- Apply for Medicaid, if eligible.
- NOTIFY PHCP OF ANY CHANGES (insurance, income, address, etc.).



"Ashley and Amanda playing together"  
by Ashley Malczewski





## 5. DETERMINATION

PHCP will inform the family of its decision within 45 days after the fully completed application has been received. Copies of this decision will be sent to the family and the providers.

**APPROVAL:** If the family has been approved they will be sent a letter of approval and a copy of the authorization of services. The provider will also receive a copy of each. The authorization specifies the services PHCP will cover for the child, the provider who will dispense care and the time period during which coverage will be in effect. The authorization will also state the level of copayment to be paid by the family for those services.



### Provider Responsibilities:

- Review authorization and inform PHCP of any errors, changes or amendments.
- Bill Erie County Health Department in accordance with authorization.
- Bill parent for copayment amount.

### Parent Responsibilities:

- Keep authorization and inform PHCP of any changes, errors or amendments.
- Be aware of dates of coverage. Services provided outside these dates will not be covered.
- Make note of copayment. *Failure to pay copayment may result in being dropped from the program.*

**NOTE:** If you believe that a service related to your child's disability should be covered and is not on the authorization, contact PHCP and speak to program staff.

**DENIAL:** If a family is ineligible for PHCP, a letter of denial will be sent to the family and the requesting physician. Service may be denied if:

1. The child is over 21.

2. The child is not a resident of Erie County.
3. The diagnosis or services are not covered by PHCP.
4. The specialty physician failed to provide requested medical justification.
5. The family failed to provide financial information.
6. The adjusted family income exceeds the financial eligibility limits.
7. The family failed to apply for Medicaid if instructed to do so.

The letter of denial will contain an explanation of the reasons for denial and an explanation of the appeal process. The parent has the right to a hearing to appeal any determination made by PHCP.

**Parent Responsibility:**

- Send a written request for a hearing to the Erie County Commissioner of Health within 45 days of receipt of the PHCP notice of denial.

### III. RECERTIFICATION



The family must recertify each year. The financial information provided in the initial application is good for 12 months from the date the family is approved. All authorizations for services, those in the original authorization and those incoming during the year, end with the financial year. It is the provider's responsibility to send in the renewal request. PHCP recommends that parents contact the provider at least 2 months prior to their expiration date to insure continuous coverage.

**Provider Responsibility:**

- Send in the renewal request before coverage expires.

**Parent Responsibility:**

- Follow up with provider to be certain recertification paperwork is submitted each year.

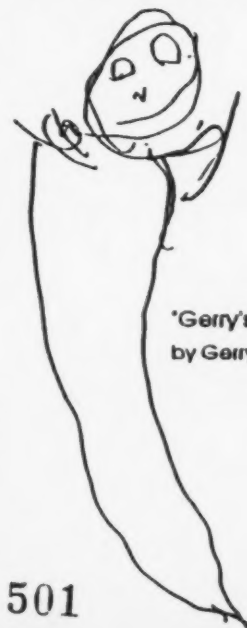
#### IV. BILLING AND INSURANCE

- PHCP is the payor of last resort. All health insurance and/or Medicaid must be fully utilized before a bill can be submitted to PHCP.
- PHCP may only be billed by the provider of services. PARENTS SHOULD NOT SUBMIT THEIR BILLS TO PHCP<sup>3</sup>.
- Parents should not pay for any PHCP authorized services out of their own pocket, other than PHCP copayments required by the program. PHCP CANNOT REIMBURSE PARENTS.
- All bills must be submitted within 90 days of service or PHCP will not cover them.
- Providers are not permitted to bill parents after receiving PHCP payment unless the family is required, under the Program, to pay a copayment.
- PHCP copayments must be paid or the family may be dropped from the program.
- If the insurance company sends a check to the family as full or partial payment for PHCP authorized services, the check must be endorsed and forwarded to the provider, or the family may be dropped from the Program.

<sup>3</sup> There are a certain few services where PHCP will directly reimburse a parent. One example is out-of-town lodging and meals for a child who requires treatment in another city. However, in these cases, PHCP staff will contact the family to explain the reimbursement process.

##### 1. BASIC INSURANCE

The insurance company is usually billed directly by the providers themselves. The insurance company will either pay all or part of the bill or reject it completely. The payment, accompanied by an explanation of benefits, is usually sent to the provider. A copy of the



'Gerry's Dad'  
by Gerry Chapman



explanation of benefits is sent to the family. Explanations of benefits also accompany rejections. The provider then submits the balance of the bill and the explanation of benefits to PHCP. PHCP will pay the balance, less the family's copayment, up to the New York State approved Medicaid rate. An explanation of benefits must accompany all bills submitted to PHCP as proof that your insurance has been fully utilized. If the insurance company sends a check to the parents as full or partial payment for services authorized by PHCP, the check must be endorsed and forwarded along with the explanation of benefits to the

provider. PHCP will then be billed for the balance less the copayment. However, if the insurance payment is made directly to the provider, the parent must follow up to make sure the payment has been made. When insurance does not cover a service but PHCP has approved the service for payment, the parents must obtain a rejection statement from their insurance company and forward the statement to the provider. The provider will then bill PHCP.

## **2. MAJOR MEDICAL**

If the family's insurance has a major medical rider, the provider will bill the basic insurance directly. The parent is responsible for submitting claims to the major medical portion of his policy. Any payments, rejections and explanations of benefits are forwarded to the provider and submitted to PHCP as before.

## **3. HEALTH MAINTENANCE ORGANIZATIONS (HMO)**

If the family is covered by an HMO, the parent must follow all the rules of the HMO. The parent must get the proper referrals for service and utilize participating providers before PHCP will pay for services. If a claim is rejected because the parent failed to obtain a referral or use an approved provider, PHCP will not pay the bill.

## **4. MEDICAID**

When a child is covered by Medicaid, the bills for most services are completely covered. However, services that require Medicaid prior approval may also require review by PHCP. The parent should contact his provider if there is a question.

## **5. NO INSURANCE OR MEDICAID**

Bills are submitted directly to PHCP by the provider. PHCP will pay the bills for authorized services at the New York State approved Medicaid rate, less the amount of PHCP copayment assessed to the family.

## **V. OTHER SERVICES:**

### **1. DIAGNOSTIC SERVICES/DIAGNOSIS AND EVALUATION**

These services can be provided for any child who is suspected having a diagnosis that is covered by PHCP, irregardless of family income. The child must be a resident of New York State and be less than 21 years of age. The diagnostic services must be provided by an approved specialist or by an approved center. **PRIOR APPROVAL MUST BE OBTAINED FOR THESE SERVICES.**

### **2. SERVICE COORDINATION/CASE MANAGEMENT**

Families of children with special health needs often require a range of services not provided by any one social or health agency, and may lack knowledge or ability to use other available services. PHCP case managers are trained to link families to the wide range of resources available in the community to help their children. These resources may include financial, medical, educational, emotional support and legal services.

The PHCP case manager works with the family to assess needs, develop a plan to meet those needs, arrange and coordinate the delivery of essential goods and services and monitor progress. The case manager also maintains close contact with the family and other service providers to insure that what has been agreed upon is provided in a timely manner. The Program is authorized to provide case management for the care at home and home and community based medicaid waivers, and for the Early Intervention Program.

This service is available to the family of any PHCP medically eligible child under 21 years of age, regardless of financial status. There is no fee for this service. If you have questions regarding PHCP Service Coordination call 858-8575.



### 3. NURSING SERVICES

PHCP may cover nursing services under certain circumstances. Additional medical justification and specific forms will be required from the referring specialty physician.

### 4. OUT-OF-TOWN SERVICES



Out-of-town services may be covered but must have pre-authorization from the medical director of the Erie County Health Department. Out-of-state services require pre-authorization from the New York State Department of Health. The physician recommending out-of-town care must provide PHCP with documentation explaining why this care is to be given out-of-town.

If approved, PHCP can reimburse families for travel, meal and lodging costs for the child only.

Travel by private car is not reimbursable. Travel by specialty vehicle, like an ambulance or Mercy Flight, may be covered if requested and medically justified by the specialty physician. Receipts are necessary for any costs to be reimbursed. Parents must contact PHCP before going out of town.

**NOTE:** In an emergency, the physician recommending out-of-town care should call PHCP to inform it of the situation and promptly file a written Recommendation of Medical Services and medical justification for out-of-state care.

#### Provider Responsibilities:

- Inform PHCP of the need for out-of-town services.
- File a Recommendation for Medical Services form with PHCP.
- Provide PHCP with medical justification and documentation if necessary.

#### Parent Responsibilities:

- Contact PHCP before going out of town.
- Save all receipts for reimbursable expenditures.

#### PHCP Responsibilities:

- Contact NYSDOH for prior approval of out-of-state care.



## 5. DRUGS AND PHARMACEUTICALS

PHCP will cover drugs that are appropriate for an eligible child's diagnosis and other related conditions if there is medical justification. PHCP will cover drugs only from participating pharmacies, and will pay only after all other sources of health insurance have been fully utilized. Pre-authorization is necessary. The list of participating pharmacies is available at specialty clinics and through PHCP. Note: If the child is covered by Health Care Plan, the Health Care Plan pharmacy must be used.

### Procedure for PHCP drug coverage:

- The parent should request the list of participating pharmacies at the specialty clinic and choose a pharmacy that is convenient for them.
- The parent should be given a prescription attached to a standard letter of introduction to the pharmacy they have chosen.
- The parent must present the letter and the prescription at the participating pharmacy along with any other insurance prescription coverage information they may have.
- The pharmacist fills the prescription and keeps the letter on file. No payment is due at this time.
- When the pharmacist receives an Erie County PHCP authorization (copies are sent to clinic and parents), he bills PHCP for services rendered. The parent is then billed the amount of copayment previously established by PHCP. The parent is responsible for the copayment at the time of service at all following visits.
- If the patient is not eligible or the drug is not covered, PHCP sends a withdrawal letter to the clinic, pharmacy and parent. The pharmacist then bills the parent for services rendered. The parent has the right to a hearing to appeal any determination made by PHCP.



#### **Clinic Responsibilities:**

- Provide the parent with the list of participating pharmacies.
- Provide the parent with the letter of introduction and the prescription.
- Forward a request for medical services to Erie County PHCP including pharmacy chosen and the drug to be covered.
- Verify the drug requested is approved for the child's diagnosis.
- Provide any further information or medical justification as necessary.

#### **Parent Responsibilities:**

- Choose a participating pharmacy.
- Report any changes in choice of pharmacy to PHCP staff.
- Provide the pharmacy with all other insurance prescription coverage information.
- Pay copayment as assessed by PHCP.
- Pay for any drugs already provided if found to be ineligible by PHCP.

For more information about any of these services, call the Erie County PHCP Office at **858-7685**.

*Thanks to Veronica Kozel for preparing the text.*

*Thanks to the students of Bornhava for providing childrens' artwork.*



**PHYSICALLY  
HANDICAPPED  
CHILDREN'S  
PROGRAM**

95 Franklin Street • Room 800  
Buffalo, New York 14202  
**716/858-7685**

**DENNIS T. GORSKI**  
COUNTY EXECUTIVE

**ARNOLD N. LUBIN, M.D.**  
COMMISSIONER OF HEALTH

*Erie County does not discriminate on account of age, sex, religion, handicap,  
national origin, color, sexual orientation, marital status or sponsor.*

**DOES YOUR  
CHILD  
HAVE SPECIAL  
HEALTH  
NEEDS?**



*'Gerry'*  
by Gerry Chapman

**PHCP CAN HELP!**

## WHAT IS PHCP?

PHCP is the Physically Handicapped Children's Program (*sometimes called "State Aid"*). Its purpose is to make high quality medical care available to children up to 21 years old who have serious medical or handicapping conditions.



## WHO IS ELIGIBLE?

Eligibility for this program depends upon the child's medical diagnosis and the family's financial status. Some of the conditions covered by the program are:

- Apnea
- Prematurity
- Congenital Heart Defects
- Cleft Palate
- Cerebral Palsy
- Cystic Fibrosis
- Orthopedic Problems
- Diabetes
- Blood Diseases
- Childhood Cancer
- Chronic Kidney Disease
- Seizure Disorders
- Profound Hearing Loss
- Spina Bifida
- Serious Congenital Physical Defects

Family financial information will be reviewed by the program staff to determine eligibility.

## WHAT SERVICES ARE AVAILABLE?

PHCP will help pay for medically necessary diagnostic treatment and rehabilitation services or equipment requested by a New York State approved physician for an eligible child.

## WHO PAYS?

PHCP will help pay for authorized services after your insurance has paid their share. The financial review will determine PHCP's share. Parents will pay the remaining portion of the costs, if any.

## HOW TO APPLY?

To start the application process call the Physically Handicapped Children's Program at **858-7685** and speak to Program Staff.

## **SERVICE COORDINATION/ CASE MANAGEMENT**

Families with physically disabled or chronically ill children often need a range of services: emotional, legal, educational and financial as well as medical. PHCP service coordinators will provide information and resources and help families learn to coordinate their own services. This service is available to any family with a chronically ill or disabled child under 21 regardless of financial status. *There is no fee for this service.* If you have questions regarding PHCP Service Coordination, call 858-8575.



### **PHYSICALLY HANDICAPPED CHILDREN'S PROGRAM**

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ECID - 4/91



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**Have You Heard  
About**



**PHCP  
Case Management**

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### **What Is PHCP Case Management?**

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Case Management is a new service provided by the Erie County Health Department's Physically Handicapped Children's Program (PHCP) to help families of children with special health needs identify and meet their goals. A professional case manager works with the child and family to assess needs, develop a plan to meet those needs, arrange and coordinate the delivery of essential goods and services and monitor progress. The case manager also maintains close contact with the family and other service providers to ensure that these needed goods and services are provided in a timely manner, and that planned services are indeed delivered.

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### **Why PHCP Case Management?**

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Managing care for a child with special health needs is often a very difficult and complex task. The child's health condition can affect many different aspects of the fami-



ly life and can sometimes become an emotional as well as economic burden. PHCP Case Management Services were developed to help families effectively cope with such difficulties.

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### **How Can PHCP Case Management Services Help?**

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Families with physically disabled or chronically ill children often need a range of services not provided by any one social or health agency and may lack knowledge or ability to use other available resources. PHCP case managers are trained to link families to the wide range of resources available to help their children. These resources include entitlement and financial assistance programs, educational services, preschool and day care programs, family support groups, counseling programs, home care and medical services, assistance with health insurance problems etc. Case managers will also advocate on behalf of children and families in order to assure that services are delivered fairly and without unnecessary delay. Finally, PHCP staff will help families become effective case managers for their own children by teaching and enabling them to make linkages, follow through with service providers and advocate on their own behalf.

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## Who Is Eligible for PHCP Case Management?

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Any family of a child, 0 to 21 years of age, with a physical disability or chronic illness and residing in Erie County may be eligible for case management services. *(A list of approved PHCP Diagnoses is available by calling the Erie County Health Department PHC Program at 858-7685).* The family requesting this service need only express the specific concern with which they wish to have help, and be willing to participate in the case management process. There is *no* fee for this service.

*If you have any other questions regarding PHCP Case Management call:*

**858-8575**

*Erie County does not discriminate on account of age, sex, religion, handicap, national origin, color, sexual orientation, marital status or sponsor.*

THE ERIE COUNTY  
DEPARTMENT OF HEALTH



Dennis T. Gorski  
County Executive

Arnold N. Lubin, M.D.  
Commissioner of Health

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**GUIA PARA FAMILIAS  
QUE QUIERAN PARTICIPAR  
EN PHCP**



**'Gerry's Dad'**  
by Gerry Chapman

## **GUIA PARA FAMILIAS QUE QUIERAN PARTICIPAR EN PHCP**

### **I. RESUMEN DEL PROGRAMA**

PHCP es el Programa para Niños con Incapacidad Física (a veces llamado Ayuda del Estado o "State Aid"). Su propósito es brindar cuidado médico de alta calidad a niños con serias condiciones médicas o de incapacidad. Para ser elegible para este programa, el niño/a debe ser residente del Condado de Erie y debe ser menor 21 años. La elegibilidad también depende del diagnóstico médico del niño/a y de la situación financiera de la familia. Algunas de las condiciones cubiertas por el programa son: premadurez, defectos cardíacos congénitos, fisura del paladar, parálisis cerebral, fibrosis quística, problemas ortopédicos, diabetes, enfermedades de la sangre, cáncer infantil, enfermedad crónica de los riñones, desórdenes con convulsiones, pérdida profunda del oído, espina bífida y defectos físicos congénitos serios. PHCP pagará por el diagnóstico médico necesario, el tratamiento, y los servicios de rehabilitación o el equipo solicitados para un niño/a elegible, por un médico aprobado por el Estado de Nueva York.

### **PRE-AUTORIZACION/APROBACION PREVIA**

Este programa tiene estándares específicos para el tratamiento de varias condiciones y no cubrirá ningún tratamiento que no cumpla con estos estándares. En general, el diagnóstico y el tratamiento deben ser prestados por uno de los médicos incluidos en la lista del Directorio de Especialistas Aprobados por el Estado de Nueva York. El diagnóstico, evaluación y tratamiento deben ser brindados, al menos parcialmente, en un centro aprobado por la División de Servicios Especiales para Niños del Departamento de Salud de Estado de Nueva York. Todo tratamiento y servicio, excepto en caso de emergencia, deben ser aprobados ANTES de ser brindados. Bajo ciertas circunstancias, PHCP aprobará en forma retroactiva de solicitudes de pago por servicios, siempre y cuando la oficina de PHCP reciba tal solicitud no menos de 90 días después de que se haya prestado tales servicios.

### **PAGADOR EN ULTIMA INSTANCIA**

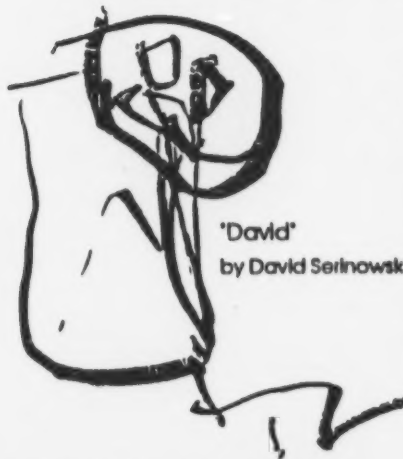
PHCP no sustituye al seguro médico. PHCP ayudará a pagar por servicios autorizados solo después de que todas las fuentes de seguro médico hayan sido utilizadas completamente.

## PAGO COOPERATIVO

El programa opera dentro de un sistema de pago cooperativo. La información financiera de la familia es revisada por el personal del programa para determinar si la familia necesitará pagar parte de los servicios y qué porcentaje de la cantidad total. Después de que la compañía de seguros ha pagado su parte por un servicio aprobado, la familia paga su porcentaje de pago cooperativo y PHCP paga el resto, hasta el límite de Medicaid aprobado por el Estado.

## II. PROCESO DE APLICACION

El proceso de aplicación incluye varios pasos:



- 1.) solicitud de servicios
- 2.) revisión general de elegibilidad
- 3.) revisión médica
- 4.) revisión financiera
- 5.) determinación final

Cuando todos estos pasos hayan sido completados, la familia será notificada de la decisión del programa.

### 1. SOLICITUD DE SERVICIOS

Un médico especialista aprobado por el Estado de Nueva York debe aplicar o solicitar cobertura de servicios para un niño/a<sup>1</sup>. Los padres no pueden aplicar. Los padres deben firmar el formulario que confirma la solicitud de servicios y da consentimiento para que la información médica del niño/a sea compartida con las partes involucradas. La solicitud debe ser entregada ANTES de que se brinde el servicio o tratamiento. Sin embargo, bajo circunstancias especiales, el programa PHCP del Condado de Erie aceptará solicitudes que lleguen máximo 90 días después de la fecha en que se hayan dado los servicios. Después de estos 90 días de límite, las solicitudes de pago de servicios no serán aceptadas.

<sup>1</sup> En el Condado de Erie, los padres, en la mayoría de casos, solicitan al Departamento de Cuentas de Pacientes del Hospital de Niños de Buffalo (Children's Hospital of Buffalo) que inicie una solicitud de servicios.



#### **Responsabilidades de los Padres:**

- Proveer la información requerida.
- Firmar la Confirmación y Consentimiento Paternal (Formulario Azul).

#### **Responsabilidades del Proveedor de servicios<sup>2</sup>:**

- Completar totalmente la Recomendación de Servicios Médicos (Formulario DOH 696).

<sup>2</sup> Un proveedor es una persona o un grupo que provee bienes o servicios médicos pertinentes a PHCP. Por ejemplo: médico especialista, clínicas, farmacias, etc.

## **2. REVISION GENERAL DE ELIGIBILIDAD**

La solicitud de servicios es revisada por el personal del programa para determinar si la información general incluida está dentro de los límites del programa. Por ejemplo, la persona que revisa la solicitud determinará si el niño/a es residente del Condado de Erie, si es menor de 21 años y si su diagnóstico está dentro de la lista aprobada hoy.



## **3. REVISION MEDICA**

La información enviada por el especialista es revisada por el Director Médico de PHCP para determinar:

1. que el diagnóstico del niño/a sea uno de los que PHCP cubre.
2. que los servicios solicitados sean apropiados para el diagnóstico.
3. que los servicios solicitados sean cubiertos por PHCP.
4. que los servicios sean brindados por un proveedor aprobado por el Estado de Nueva York.

Información adicional y/o justificación médica pueden ser solicitadas del proveedor. Copias de estas solicitudes son enviadas a los padres.

#### **Responsabilidades del Proveedor:**

- Entregar la información adicional o justificación médica máximo 10 días después de recibir la solicitud.

#### **Responsabilidades de los Padres:**

- Hacer un seguimiento para asegurarse de que las solicitudes de información adicional o justificación médica sean cumplidas, según sea necesario.

#### 4. REVISION FINANCIERA

Un formulario de aplicación es enviado a la familia para que ésta lo complete y devuelva con una verificación de ingresos y con información sobre el seguro médico. Esta información será revisada por el personal de PHCP para determinar si los ingresos ajustados de la familia entran dentro de los límites del programa y para establecer cuál sería su nivel de pago cooperativo. Se requerirá que la familia aplique para recibir Medicaid en caso de que califique para ese programa.

##### Responsabilidades de PHCP:

- Revisar la información financiera.
- Determinar la elegibilidad financiera.
- Determinar el nivel de pago cooperativo de la familia.

##### Responsabilidades de los Padres:

- Completar totalmente y enviar la aplicación.
- Entregar COPIAS del formulario de impuestos 1040 del año anterior (incluyendo todas las descripciones o horarios) y de los cuatro últimos talones de pago de salario.
- Proveer cualquier documentación de ingresos adicional requerida por PHCP.
- Incluir una COPIA, de los dos lados, de cualquier tarjeta de seguro.
- Aplicar a Medicaid, si es necesario.
- NOTIFICAR A PHCP SOBRE CUALQUIER CAMBIO (seguro, ingresos, dirección, etc.)



"Ashley and Amanda playing together"  
by Ashley Malczewski



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## 5. DETERMINACION

PHCP informará a la familia de su decisión 45 días después de haber recibido la aplicación completa. Las copias de esta decisión serán enviadas a la familia y a los proveedores.

**APROBACION:** Si ha sido aprobada, la familia recibirá una carta de aprobación. Adicionalmente, la familia y todos los proveedores también recibirán una copia de la autorización de servicios. La autorización especifica qué servicios requeridos por el niño/a serán cubiertos por PHCP, cuáles proveedores prestarán esos servicios y durante cuánto tiempo será efectiva tal cobertura. La autorización también indicará el porcentaje de pago cooperativo que debe ser cubierto por la familia por tales servicios.



### Responsabilidades del Proveedor:

- Revisar la autorización e informar a PHCP de cualquier error, cambio o enmienda.
- Enviar las cuentas al Departamento de Salud del Condado de Erie, según la autorización.
- Enviar a los padres las cuentas por su parte de pago cooperativo.

### Responsabilidades de los Padres:

- Guardar la autorización entre sus documentos y como prueba de autorización.
- Revisar la autorización e informar a PHCP de cualquier cambio, error o enmienda.
- Estar alerta a las fechas de cobertura. Los servicios dados fuera de esas fechas no serán cubiertos por PHCP.
- Tomar en cuenta su responsabilidad de pago cooperativo. *Si la familia no hace sus pagos cooperativos puede ser eliminada del programa.*

**NOTA:** Si los padres piensan que un servicio relacionado con la incapacidad de su hijo/a debería ser cubierto y no ha sido autorizado por este programa, deben llamar a PHCP y hablar con el personal del programa.

**NEGACION:** Si una familia no es elegible para el programa de PHCP, una carta de negación será enviada a la familia y al médico que haya solicitado los servicios. El servicio puede ser negado si:

1. el niño/a es mayor de 21 años.
2. el niño/a no es residente del Condado de Erie.
3. el diagnóstico o los servicios no están dentro de la lista de los que PHCP cubre.
4. el médico especialista no envió la justificación médica solicitada.
5. la familia no entregó la información financiera.
6. los ingresos ajustados de la familia exceden los límites de elegibilidad.
7. la familia no aplicó a Medicaid cuando se le indicó que lo haga.

La carta de negación contendrá una explicación de las razones por las que la solicitud fue negada y una explicación del proceso de apelación. Los padres tienen el derecho a una audiencia para apelar cualquier decisión hecha por PHCP.

**Responsabilidad de los Padres:**

- Enviar por escrito una solicitud pidiendo una audiencia al Erie County Commissioner of Health, 95 Franklin Street, Buffalo, New York 14202, máximo 45 días después de recibir la nota de negación de PHCP.

### III. RE-CERTIFICACION

La familia debe ser re-certificada cada año. La información financiera provista en la aplicación inicial es válida por 12 meses desde la fecha en que la familia es aprobada. Todas las autorizaciones de servicios, aquellas en la autorización original y aquellas que vengan durante el año, terminan al final del año financiero. Es la responsabilidad del proveedor enviar la solicitud de renovación.

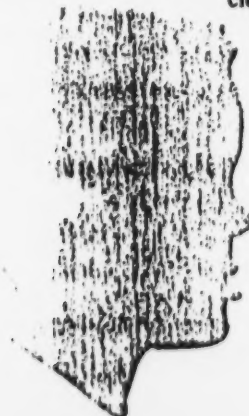
PHCP recomienda que los padres se pongan en contacto con el proveedor por los menos 2 meses antes de la fecha de expiración para asegurarse que la cobertura sea continua.

**Responsabilidad del Proveedor:**

- Enviar la solicitud de renovación antes de que la cobertura expire.

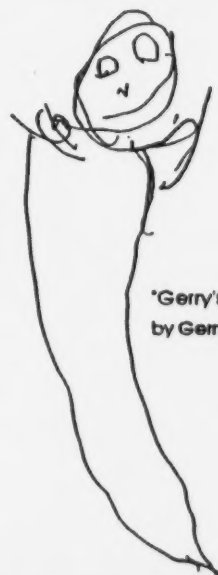
**Responsabilidad de los Padres:**

- Hacer un seguimiento para asegurarse de que el proveedor complete cada año el papeleo de re-certificación.



#### IV. CUENTAS Y SEGURO

- PHCP es el pagador de última instancia. Todo seguro médico y/o Medicaid deben ser utilizados completamente antes de enviar una cuenta a PHCP.
- PHCP recibe cuentas enviadas únicamente por el proveedor de servicios. **LOS PADRES NO DEBEN ENVIAR SUS CUENTAS A PHCP**<sup>3</sup>.
- No pague por ningún servicio autorizado por PHCP directamente, excepto por su parte de pago cooperativo. **PHCP NO LE REEMBOLSA ESE DINERO.**
- Toda cuenta debe ser entregada con un máximo de 90 días después de la fecha de servicio, o PHCP no pagará por tal servicio.
- No se permite que los proveedores envíen las cuentas a los padres después de recibir el pago de PHCP, a no ser que la familia deba, bajo este Programa, pagar cooperativamente.
- Los pagos cooperativos con PHCP (a diferencia de pagos cooperativos con seguros médicos) deben ser cumplidos, o la familia será eliminada del programa.
- Si la compañía de seguros envía un cheque a la familia como pago total o parcial por servicios autorizados por PHCP, el cheque debe ser endosado y enviado al proveedor. De no hacerlo, la familia será eliminada del Programa.



"Gerry's Dad"  
by Gerry Chapman

<sup>3</sup> Hay unos pocos servicios para los cuales PHCP reembolsará directamente a los padres. Un ejemplo es el pago de alojamiento y comida de un niño/a que necesite recibir tratamiento en otra ciudad. Sin embargo, en estos casos, el personal de PHCP se pondrá en contacto con la familia para explicar el proceso de reembolso.

## 1. SEGURO BASICO



La compañía de seguros generalmente recibe las cuentas directamente del proveedor de servicios. La compañía de seguros puede pagar toda la cuenta, o pagar parte de ella, o rechazarla completamente. El pago, acompañado por una explicación de los beneficios, es usualmente enviado al proveedor. Una copia de la explicación de beneficios también es enviada a la familia. Explicaciones de beneficios también son incluidas en las notificaciones de rechazo.

El proveedor entonces envía el balance de la cuenta y la explicación de beneficios a PHCP. PHCP pagará el balance, menos la parte de pago cooperativo que le corresponde a la familia, hasta el nivel de Medicaid aprobado por el Estado de Nueva York. Una explicación de beneficios debe acompañar todas las cuentas enviadas a PHCP como prueba de que el seguro de los padres ha sido utilizado completamente. Si la compañía de seguros envía un cheque a los padres como pago total o parcial por los servicios autorizados por PHCP, el cheque debe ser endosado y enviado junto con la explicación de beneficios al proveedor. PHCP entonces recibirá una cuenta por el balance, menos la cantidad de pago cooperativo. Sin embargo, si el pago de seguro se supone será enviado directamente al proveedor, los padres deben hacer un seguimiento para asegurarse de que el pago haya sido recibido. Cuando el seguro no cubre un servicio pero PHCP ha aprobado el pago de ese servicio, los padres deben obtener una declaración de la compañía de seguros y enviar tal declaración al proveedor. El proveedor entonces enviará la cuenta a PHCP.

## 2. SEGURO MEDICO MAYOR ("MAJOR MEDICAL")

Si el seguro de la familia tiene una póliza de seguro médico mayor, el proveedor enviará la cuenta directamente al seguro básico. Los padres son responsables por el envío de reclamos por la porción de seguro médico mayor ("major medical") de su póliza. Todo pago, rechazo y explicación de beneficios son enviados al proveedor y enviados a PHCP, como se explicó anteriormente.

## 3. ORGANIZACIONES PARA EL MANTENIMIENTO DE LA SALUD (HMO)

Si la familia está cubierta por una HMO, los padres deben seguir las reglas de tal organización. Los padres deben conseguir las referencias apropiadas para servicio y acudir a los proveedores que participen en ese programa antes de que PHCP pague por los servicios. Si un reclamo es denegado porque los padres no obtuvieron una referencia o no acudieron a un proveedor aprobado por la HMO, PHCP no pagará la cuenta.



#### 4. MEDICAID

Cuando un niño/a está cubierto por Medicaid, las cuentas por la mayoría de servicios están completamente cubiertas. Sin embargo, los servicios que requieren aprobación previa de Medicaid también pueden requerir una revisión por PHCP. Los padres deben contactar al proveedor si tienen alguna pregunta.

#### 5. FAMILIAS SIN SEGURO NI MEDICAID

Las cuentas se envían directamente a PHCP por el proveedor. PHCP pagará las cuentas por los servicios autorizados al nivel de Medicaid aprobado por el Estado de Nueva York, menos la cantidad de pago cooperativo determinado para la familia.



### V. OTROS SERVICIOS:

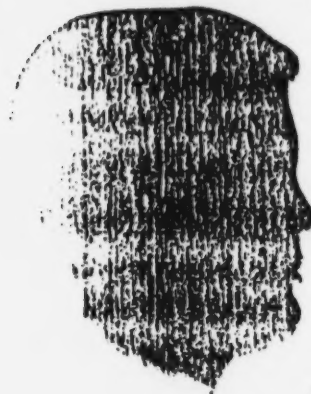
#### 1. SERVICIOS DE DIAGNOSTICO/ DIAGNOSTICO Y EVALUACION

Estos servicios pueden ser prestados para un niño/a que se sospeche tenga uno de las condiciones cubiertas por PHCP, cualquiera sea el ingreso de la familia. El niño/a debe ser residente del Estado de Nueva York y debe ser menor de 21 años. Los servicios de diagnóstico deben ser provistos por un especialista aprobado o por un centro aprobado. SE DEBE OBTENER APROBACION PREVIA PARA ESTOS SERVICIOS.

#### 2. SERVICIO DE COORDINACION/MANEJO DE CASOS

Las familias de niños con necesidades médicas especiales a menudo requieren una variedad de servicios que no son prestados por una sola agencia social o de salud. Los manejadores de casos de PHCP están entrenados para conectar a las familias con una gran cantidad de recursos disponibles en la comunidad para ayudar a estos niños, recursos que las familias desconocen o no saben utilizar. Estos recursos incluyen servicios financieros, médicos, educativos, legales y de apoyo emocional.

El manejador de casos de PHCP trabaja con la familia para evaluar sus necesidades, desarrollar un plan para satisfacer esas necesidades, coordinar la provisión de los bienes y servicios esenciales y supervisar su progreso. El manejador de casos también mantiene contacto cercano con la familia y otros proveedores de servicios para asegurarse de que los bienes y servicios requeridos sean brindados a tiempo.



Este servicio está a la disposición de la familia, cualquiera sea la situación financiera, que tenga un niño/a, menor de 21 años, médicamente elegible para participar en PHCP. Este servicio es gratuito.

### 3. SERVICIOS DE ENFERMERIA

PHCP puede cubrir el costo de servicios de enfermería bajo ciertas circunstancias. Se requerirán justificaciones médicas adicionales y formularios específicos del médico especialista que haya hecho la referencia.

### 4. SERVICIOS FUERA DE LA CIUDAD

Los servicios fuera de la ciudad pueden ser cubiertos pero debe recibir pre-autorización del Director Médico del Departamento de Salud del Condado de Erie. Los servicios fuera del estado requieren la pre-autorización del Departamento de Salud del Estado de Nueva York. El médico que recomiende cuidado fuera de la ciudad debe dar a PHCP la documentación que indique por qué tal servicio debe prestarse fuera de la ciudad. Si es aprobado, PHCP puede reembolsar a las familias por gastos de viaje, comida y alojamiento del niño/a únicamente. El costo de viajes en automóvil privado no son reembolsables. El costo de viajes en un vehículo especial (por ejemplo, una ambulancia o por vía aérea en "Mercy Flight"), pueden ser cubiertos si son solicitados y son médicamente justificables por el especialista. Los padres deben presentar recibos como prueba de todos los costos que vayan a ser reembolsados. Los padres deben ponerse en contacto con PHCP antes de ir a otra ciudad para el servicios.

NOTA: En una emergencia, el médico que recomiende tratamiento fuera de la ciudad debe llamar a PHCP para informar al personal de la situación y presentar una formulario escrito de Recomendación de Servicios Médicos y una justificación médica para el servicio fuera del estado.

#### **Responsabilidades del Proveedor:**

- Informar a PHCP de la necesidad de servicios fuera de la ciudad.
- Presentar a PHCP un formulario de Recomendación de Servicios Médicos.
- Entregar a PHCP una justificación médica y la documentación necesaria.

#### **Responsabilidades de los Padres:**

- Contactar a PHCP antes de ir a otra ciudad para recibir servicios.
- Guardar todos los recibos como prueba de los gastos que vayan a ser reembolsados.

#### **Responsabilidades del Programa:**

- Contactar NYSDOH para obtener aprobación previa para recibir servicios fuera del estado.

### **5. MEDICINAS Y PRODUCTOS FARMACEUTICOS**

PHCP cubrirá la mayoría de medicinas apropiadas para un diagnóstico aprobado y para otras si hay justificación médica. PHCP cubrirá el costo de medicinas únicamente en las farmacias que participen en el programa, y pagará solamente después de que todas las fuentes de seguro médico hayan sido completamente utilizadas. Se necesita pre-autorización. La lista de farmacias participantes está a su disposición en las clínicas de especialidades y a través de PHCP. Nota: Si el niño/a está cubierto por Health Care Plan, se debe acudir a la farmacia de Health Care Plan.



**'Becky'**  
by Rebecca Hake

#### **Procedimiento para la cobertura de medicinas por PHCP:**

- Los padres deben pedir la lista de farmacias participantes en la clínica de especialidades y escoger una farmacia que sea conveniente para ellos.
- Los padres deben recibir una receta junto con una carta estándar de introducción a la farmacia que hayan escogido.

- Los padres presentan la carta y la receta en la farmacia participante junto con cualquier información de otro seguro que cubra medicinas.
- El farmacéutico les entrega las medicinas indicadas en la receta y guarda la carta en el expediente del paciente. No se necesita pagar en ese momento.
- Cuando la farmacia recibe una autorización de PHCP del Condado de Erie (copias son enviadas a las clínicas y a los padres), el farmacéutico envía una cuenta a PHCP por los servicios prestados. Los padres entonces reciben una cuenta por la porción de pago cooperativo determinada anteriormente por PHCP. Los padres son responsables por pagar su parte al momento en que el servicio se preste en las siguientes visitas.
- Si el paciente no es elegible o la medicina no está cubierta, PHCP envía una carta de retiro a la clínica, a la farmacia y a los padres. El farmacéutico entonces envía la cuenta por los servicios prestados a los padres. Los padres tienen derecho a una audiencia para apelar cualquier decisión hecha por PHCP.

#### **Responsabilidades de la Clínica:**

- Proveer a los padres una lista de las farmacias participantes.
- Proveer a los padres una carta de introducción y la receta médica.
- Enviar una solicitud de servicios médicos a PHCP del Condado de Erie, incluyendo el nombre de la farmacia escogida y de las medicinas que van a ser cubiertas.
- Verificar que las medicinas solicitadas sean aprobadas para el diagnóstico del niño/a.
- Proveer cualquier otra información o justificación medica necesaria.

#### **Responsabilidades de los Padres:**

- Escoger una farmacia participante.
- Informar a PHCP de cualquier cambio en la selección de farmacia.
- Dar a la farmacia toda la información de otros seguros que cubran medicinas.
- Pagar la cantidad de pago cooperativo determinado por PHCP.
- Pagar por todas las medicinas que hayan recibido y que no sean cubiertas por el programa de PHCP.

Para más información sobre cualquiera de estos servicios, llame a la Oficina de PHCP del Condado de Erie al **858-7685**.

*Thanks to Veronica Kozel for preparing the text.*

*Thanks to the students of Bornhava for providing childrens' artwork.*



**PHYSICALLY  
HANDICAPPED  
CHILDREN'S  
PROGRAM**

95 Franklin Street • Room 800  
Buffalo, New York 14202  
**716/858-7685**

**DENNIS T. GORSKI**  
COUNTY EXECUTIVE

**ARNOLD N. LUBIN, M.D.**  
COMMISSIONER OF HEALTH

*Erie County does not discriminate on account of age, sex, religion, handicap,  
national origin, color, sexual orientation, marital status or sponsor.*

**¿TIENE SU HIJO  
NECESIDAD DE  
CUIDADO MEDICO  
ESPECIAL?**

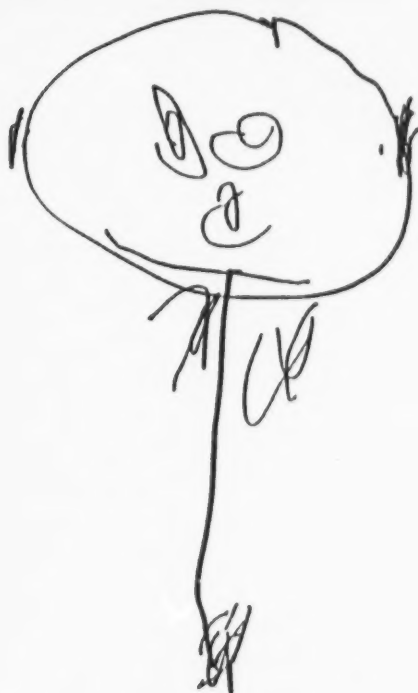


**¡PHCP PUEDE  
AYUDARLE!**



## ¿Qué es PHCP?

PHCP es el Programa para Niños con Incapacidad Física (*a veces llamado "Ayuda del Estado" o "State Aid"*). Su objetivo es poner servicio médico de alta calidad a la disposición de niños (menores de 21 años) que tengan una condición médica seria o una discapacidad.



"Amanda"  
by Amanda Davidson

## ¿Quién es elegible?

La elegibilidad para este programa depende del diagnóstico médico del niño/a y la situación financiera de la familia. Algunas de las condiciones cubiertas por este programa son:

- Apnea
- Premadurez
- Defectos Cardíacos Congénitos
- Fisura del Paladar
- Parálisis Cerebral
- Fibrosis Cística
- Problemas Ortopédicos
- Diabetes
- Enfermedades de la Sangre
- Cáncer Infantil
- Enfermedad Crónica de los Riñones
- Desórdenes con Convulsiones
- Pérdida Profunda del Oído
- Espina Bífida
- Defectos Físicos Congénitos Serios

La información financiera de la familia será revisada por el personal del programa para determinar si el niño/a es elegible.

## Qué Servicios Se Ofrecen?

PHCP ayudará a pagar el diagnóstico, el tratamiento y servicios de rehabilitación o el equipo, que un niño/a elegible necesite desde el punto de vista médico y que hayan sido solicitados por un médico aprobado por el Estado de Nueva York.

## ¿Quién Paga?

PHCP ayudará a pagar por los servicios autorizados después de que su compañía de seguro haya pagado su parte. La revisión financiera determinará la proporción que PHCP pagará. Los padres tendrán que pagar el resto del costo, si queda una porción sin pagar.

## ¿Cómo Aplicar?

Para comenzar el proceso de aplicación, llame al Programa para Niños con Incapacidad Física (PHCP) al **858-7685** y hable con el Personal del Programa.

## Coordinación de Servicios

Las familias que tienen niños con incapacidades físicas o con enfermedades crónicas a menudo necesitan una variedad de servicios: emocionales, legales, educativos y financieros, así como médicos. Los coordinadores de servicios de PHCP brindarán a las familias información sobre las fuentes de servicio disponibles, y les ayudarán a aprender a coordinar sus propios servicios. Este servicio está a la disposición de toda familia, cualquiera sea su situación financiera, que tenga un niño/a, menor de 21 años, con una incapacidad o una enfermedad crónica. *Este servicio es gratuito.* Si tiene preguntas sobre Coordinación de Servicios de PHCP, llame al 858-8575.



### PHYSICALLY HANDICAPPED CHILDREN'S PROGRAM

95 Franklin Street • Room 800  
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ECHD-7/94

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**¿Ha oído sobre el  
Servicio de**



**Manejo de Casos  
de PHCP?**

534

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## ¿Qué es el Servicio de Manejo de Casos de PHCP?

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El Manejo de Casos es un servicio brindado por el Programa para Niños con Incapacidad Física (PHCP) del Departamento de Salud del Condado de Erie para ayudar a familias que tengan niños con necesidades médicas especiales a identificar y lograr sus objetivos. Un manejador de casos profesional trabaja con el niño/a y su familia para evaluar sus necesidades, desarrollar un plan para satisfacer sus necesidades, coordinar la provisión de los bienes y servicios requeridos y supervisar su progreso. El manejador de casos también mantiene contacto cercano con la familia y con otros proveedores de servicios para asegurarse de que los bienes y servicios planificados sean brindados a tiempo y de la mejor manera.

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## ¿Por qué existe el Servicio de Manejo de Casos de PHCP?

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El manejo de casos para un niño/a con necesidades médicas especiales es a menudo una tarea difícil y compleja. La condición de salud del niño/a puede afectar muchos aspectos diferentes de la



vida familiar y puede, a veces, convertirse en una carga tanto emocional como económica. Los Servicios de Manejo de Casos de PHCP fueron desarrollados para ayudar a que las familias enfrenten efectivamente tales dificultades.

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## ¿Cómo ayudan los Servicios de Manejo de Casos de PHCP?

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Las familias que tienen niños incapacitados físicamente o crónicamente enfermos a menudo necesitan una variedad de servicios que no son brindados por una sola agencia social o de salud. Los manejadores de casos de PHCP están entrenados para conectar a las familias con una gran cantidad de recursos disponibles para ayudar a los niños, recursos que las familias desconocen o no saben utilizar. Estos recursos incluyen programas de concesiones y asistencia financiera, servicios educativos, programas preescolares y de cuidado diurno, grupos de apoyo familiar, programas de consejería, servicios médicos y de cuidado en el hogar, ayuda con problemas de seguro médico, etc.. Los manejadores de casos también intercederán por los derechos de los niños y sus familias para asegurar que los servicios sean brindados de manera justa y sin demoras innecesarias. Finalmente, el personal de PHCP enseñará a las familias a que se conviertan ellas mismas en manejadoras de casos y puedan abogar por sus hijos y hacer contactos y seguimiento para asegurarse de que los proveedores brinden los servicios apropiadamente.

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**¿Quién es elegible el Servicio  
de Manejo de Casos de  
PHCP?**

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Todo familia que tenga un niño/a, menor de 21 años y residente del Condado de Erie, con una incapacidad física o una enfermedad crónica es elegible para los servicios de manejo de casos. *(Se puede obtener una lista de Diagnósticos aprobados por PHCP llamando al Programa PHCP del Departamento de Salud del Condado de Erie al 858-7685).* La familia que solicite este servicio no tiene más que expresar cuál es el área específica en la que necesita ayuda y estar dispuesta a participar en el proceso de manejo de casos. Este servicio es gratuito.

*Si Usted tiene cualquier otra pregunta  
sobre el Servicio de Manejo de Casos  
de PHCP, llame al:*

**858-8575**

El Condado de Erie no discrimina en base a edad, sexo, religión, incapacidad, nacionalidad, color, orientación sexual, estado civil o auspiciador.



**CONDADO DE ERIE  
DEPARTAMENTO DE SALUD**

Dennis T. Gorek  
County Executive

Arnold N. Lubin, M.D.  
Commissioner



## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

*Mary H  
FyH  
Please return  
to me  
Nancy*

August 29, 1994

Ms. Nancy Kehoe, Program Director  
Physically Handicapped Children's Program  
Bureau of Child and Adolescent Health  
New York State Department of Health  
Corning Tower, Empire State Plaza  
Albany, New York 12237

Dear Nancy:

As promised I am sending you copies of our PHCP and PHC Case Management Program materials. That have been translated into Spanish. The PHCP handbook, a new PHCP brochure and a Case Management brochure are being printed. Those pieces will be forwarded as soon as they are ready.

I hope these pieces "warm the cockles of your culturally sensitive heart". Please share them with Mary Huber.

Talk with you soon.

Sincerely,

Gary Wolfe,  
Program Coordinator  
PHCP/CHAP

**RECEIVED**  
SEP - 1 1994  
**BUREAU OF CHILD HEALTH**

Encl.  
GLW/maa

538





## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

### DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

#### PROGRAMA PARA NIÑOS CON INCAPACIDAD FÍSICA (PHCP)

95 Franklin Street  
Buffalo, New York 14202

- Propósito:** El propósito del programa PHCP (a veces llamado "State Aid" o "Ayuda del Estado") es poner cuidado médico de alta calidad a la disposición de niños menores de 21 años que tengan condiciones de incapacidad y que de otra manera no podrían pagar tal cuidado.
- Servicios:** El programa PHCP pagará por los servicios médicamente necesarios de diagnóstico, el tratamiento y rehabilitación o los equipos solicitados por un médico aprobado por el Estado de Nueva York para un niño/a elegible. PHCP pagará los costos parciales o totales de tal cuidado únicamente si no existe otro seguro o un tercer pagador que cubra estos gastos.
- Eligibilidad:** La elegibilidad para este programa depende tanto del diagnóstico médico del niño/a como de la situación financiera de la familia. Tenemos a su disposición una lista de los diagnósticos médicos aprobados actualmente por el Programa para Niños con Incapacidad Física del Condado de Erie en la oficina de PHCP, Erie County Office Building, 95 Franklin Street, Buffalo, New York, 14202. La información financiera de la familia también será revisada por el personal del programa para determinar la elegibilidad.
- Aplicación:** El médico del aplicante también debe entregar una recomendación solicitando diagnóstico (SCS-1), servicios de tratamiento o rehabilitación, o equipo (DOH-696) a la Oficina de PHCP en Edificio de Oficinas del Condado de Erie (Erie County Office Building). La solicitud debe ser entregada antes de que los servicios sean prestados. Sin embargo, bajo ciertas circunstancias, el programa PHCP del Condado de Erie procesará solicitudes que se reciban en nuestra oficina no más tarde de noventa (90) días de que se hayan brindado los servicios. Las solicitudes de pago de servicio que lleguen después de los 90 días del límite no serán aceptadas.

Las solicitudes nuevas deben ser acompañadas por el formulario de Reconocimiento y Consentimiento Paterno, que debe ser llenado y firmado por los padres o guardianes legales del niño/a. Este formulario asegura a PHCP que los padres/guardianes del niño/a dan su consentimiento para que la solicitud y cualquier otra información médica necesaria para este proceso sean enviadas a la Oficina de PHCP.

La familia de cada aplicante será contractada por un empleado de PHCP, quien revisará la información financiera de la familia para determinar su elegibilidad. Los padres/guardianes deberán proveer documentación sobre su situación financiera.

Después de la revisión final y de la aprobación por el Director Médico de PHCP, una notificación de autorización o una negación de la solicitud será enviada por correo al proveedor de servicios médicos que entregó inicialmente la solicitud. Una copia de esta carta también se enviará a los padres o guardianes del niño/a. Debido a que PHCP no emite ninguna clase de tarjeta de identificación de seguro, la descripción del tipo de cobertura que un niño/a aceptado en este programa recibirá está incluida en su carta de autorización.

Todo aplicante tiene derecho a una audiencia ante el Comisionado de Salud para revisar y apelar cualquier decisión adversa hecha por el programa. Las solicitudes para una audiencia deben hacerse por escrito máximo treinta (30) días después de la notificación de la decisión que se quiera apelar.

**Auspicio:**

El Programa para Niños con Incapacidad Física está auspiciado con fondos de la Oficina de Salud del Niño y el Adolescente del Departamento de Salud del Estado de Nueva York y por el Condado de Erie.

**Información:**

Para mayor información sobre el programa PHCP del Condado de Erie, por favor póngase en contacto con un Empleado de Admisiones llamando al 858-7685.



## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

### DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

#### PHYSICALLY HANDICAPPED CHILDREN'S PROGRAM (PHCP)

95 Franklin Street  
Buffalo, New York 14202

- Purpose:** The purpose of the PHCP (sometimes called "State Aid") is to make high quality medical care available to children up to 21 years of age with handicapping conditions, who would otherwise not be able to afford such care.
- Services:** PHCP will pay for medically necessary diagnostic, treatment and rehabilitation services or equipment requested by a New York State approved physician for an eligible child. PHCP will pay partial or total costs of such care only if there is no insurance or other third party payor to cover these expenses.
- Eligibility:** Eligibility for this program depends upon both the child's medical diagnosis and the family's financial status. A list of the currently approved medical diagnoses for the Erie County Physically Handicapped Children's Program is available from the PHCP Office, 953 Erie County Office Building, 95 Franklin Street, Buffalo, New York, 14202. Family financial information will also be reviewed by program staff to determine eligibility.
- Application:** The applicant's physician must submit a recommendation for diagnostic (SCS-1), treatment or rehabilitation services, or equipment (DOH-696) to the PHCP Office in the Erie County Office Building. The request should be submitted before care is provided. However, under certain circumstances, the Erie County PHCP will process requests that are received in our office no later than ninety (90) days after the care has been delivered. Requests for services delivered prior to this 90 day limit will not be honored.

New requests must be accompanied by a completed Parent Acknowledgement and Consent form that has been signed by the child's parent or legal guardian. This form assures PHCP that the child's parent/guardian consents to having it sent to the PHCP Office along with whatever medical information is necessary for its processing.

Each applicant's family will be contacted by a PHCP worker who will review family financial information to determine eligibility. Parents/guardians will be required to provide documentation of their financial status.

After final review and approval by the PHCP Medical Director, notification of authorization or denial of the request will be mailed to the medical service provider that initially submitted the request. A copy of this letter will also be made available to the child's parent or guardian. As PHCP does not issue an insurance identification card of any kind, coverage for each child under this program is outlined in his or her authorization letter.

Each applicant has the right to a hearing before the Commissioner of Health to review and appeal any adverse decision made by the Program. Requests for hearings must be made in writing no later than thirty (30) days after notification of the decision being appealed.

**Sponsorship:** The Physically Handicapped Children's Program is funded through the Bureau of Child and Adolescent Health of the New York State Health Department and by the County of Erie.

**Information:** For more information about the Erie County PHCP, please contact an Intake Worker at 858-7685.

Form No. PHCP-1 (rev. 6/94)

Departamento de Salud del Condado de Erie  
Programa para Niños con Incapacidad Física  
FORMULARIO DE APLICACION

La información solicitada a continuación es necesaria para determinar su elegibilidad para participar en el Programa para Niños con Incapacidad Física (PHCP). Por favor complete TODOS los espacios, excepto donde se indique lo contrario.

**PARTE 1 INFORMACION GENERAL**

Nombre del Niño/a \_\_\_\_\_ Fecha de Nacimiento 11 / 1 /      Sexo     

Dirección \_\_\_\_\_ Estado/Ciudad \_\_\_\_\_ Zip \_\_\_\_\_

Nombre del Padre, Madre o Guardián \_\_\_\_\_ Número de Personas en Casa \_\_\_\_\_

Números Telefónicos (Casa) \_\_\_\_\_ (Oficina) \_\_\_\_\_

**PARTE 2 COBERTURA DE COSTOS MEDICOS**

A. Seguro De Salud: ¿Tiene Ud. seguro médico?      SI      NO. Si contesta "NO", continúe con "B. Programas de Asistencia Médica". Si contesta "SI", complete lo siguiente:

¿Paga Ud. mismo las primas de seguro médico?      SI      NO.

Si contesta "SI", ¿cuánto paga por mes? \$ \_\_\_\_\_

| Subscritor | Compañía de Seguros | No. Identificación/<br>Certificado | Grupo | Clase | Tipo | Fecha |
|------------|---------------------|------------------------------------|-------|-------|------|-------|
|            |                     |                                    |       |       |      |       |
|            |                     |                                    |       |       |      |       |

¿Tiene este seguro una póliza de cuidado médico primario o subscritor médico mayor?      SI      NO

¿Tiene este seguro una póliza para cubrir el costo de medicinas o subscritor de recetas?      SI      NO

*Nota: El Departamento de Salud del Condado de Erie debe recibir, junto con esta aplicación, prueba de posesión del Seguro Médico que Ud. ha indicado arriba.*

B. Programas de Asistencia Médica: ¿Está recibiendo Medicaid, SSI o Asistencia Pública?      SI      NO  
Si contesta "SI", por favor indique los números de caso \_\_\_\_\_, y después continúe con la PARTE 4.  
Si contesta "NO", continúe con la PARTE 3.

**PARTE 3 SITUACION FINANCIERA (Ingresos)**

Por favor complete la información solicitada a continuación. Incluya TODAS las fuentes de ingresos en su hogar. Ud. debe entregar una copia de su más reciente formulario 1040 de declaración de impuestos federales y copias de los cuatro (4) últimos talonarios de salario, como prueba de ingresos. Ud. debe enviar prueba de todos y cada uno de los ingresos mencionados abajo, pero que no hayan sido reportados en su declaración de impuestos.

| Fuente                             | Nombre del Miembro de Familia | Cantidad Mensual Neta         |
|------------------------------------|-------------------------------|-------------------------------|
| Empleador (Nombre)                 |                               |                               |
| Empleador (Nombre)                 |                               |                               |
| Ingreso de Renta                   |                               |                               |
| Seguro Social                      |                               |                               |
| Dividendos, Interés de Banco, etc. |                               |                               |
| Pensión para Niños o Alimenticia   | 543                           |                               |
| Otros (Identifique)                |                               |                               |
| PHCP Form No. 1499 PH Rev. 5/94    |                               | PHCP STAFF USE MO. TOT. _____ |



## PARTE 4 FONDOS FINANCIEROS

Por favor complete la información solicitada a continuación. Los fondos financieros incluyen TODAS las cuentas bancarias (de ahorros, cheques, certificados de depósitos o CD, etc.) así como el valor actual en efectivo de sus valores y obligaciones.

| Fondos Financieros (ahorros, chequera, etc.) | Nombre del Banco/Compañía | Balance/Valor en Efectivo |
|----------------------------------------------|---------------------------|---------------------------|
|                                              |                           |                           |
|                                              |                           |                           |
|                                              |                           |                           |
|                                              |                           |                           |
| PHCP STAFF USE                               |                           | TOT. _____                |

¿Cuál es su pago mensual de hipoteca o de renta? \_\_\_\_\_

## PARTE 5 CERTIFICACION Y CONSENTIMIENTO (Por favor lea con cuidado antes de firmar)

**Certificación:** Al firmar esta aplicación, yo juro y afirmo que la información que he dado al Condado de Erie es completa y verdadera según mi mejor conocimiento.

**Consentimiento:** Yo entiendo que al firmar este formulario de aplicación, yo acepto cualquier investigación hecha por el Departamento de Salud del Condado de Erie para verificar o confirmar la información que he dado. Si se necesita información adicional, yo la daré, provide it.

**Acuerdo:** Yo prometo informar inmediatamente al Departamento de Salud del Condado de Erie de cualquier cambio en mis ingresos, condiciones de vida, dirección domiciliar, o cobertura de seguro médico. Yo acepto presentar los reclamos por beneficios de seguro médico o de accidente, o de cualquier otra fuente, a los que tenga derecho. Yo prometo informar al Departamento de Salud del Condado de Erie de cualquier juicio que involucre la incapacidad cubierta por esta aplicación, y de cualquier cambio que resulte en el seguro médico o de accidente. Yo acepto entregar al Departamento de Salud del Condado de Erie y/o a sus proveedores de servicios todo dinero que reciba del seguro médico por servicios cubiertos por esta aplicación. Yo acepto someterme a todos los requisitos de mi contrato de seguro médico de manera que pueda recibir todos los beneficios a los que mi hijo/a tenga derecho. *NOTA: Para asegurar la cobertura de servicios con ciertos Seguros Médicos HMO, antes recibir los servicios que necesite, Usted debe obtener la aprobación de esos servicios o pedir a su médico primario que envíe un formulario de referencia. A menudo, los servicios son cubiertos solamente si son prestados por proveedores que participan en ese programa.*

Firma: \_\_\_\_\_ Fecha: \_\_\_\_\_

## PARTE 6 DISPOSICION (Completada por el Personal del Programa)

| PHCP STAFF USE      |  |
|---------------------|--|
| A. ANN.INC.         |  |
| B. L ASS X .52      |  |
| C. SBTOT A+B        |  |
| D. DED.             |  |
| E. ADJ.ANN.INC. C-D |  |
| F. LEVEL            |  |

☐ Approved PHL      ☐ After Insurance      ☐ No Insurance      ☐ % Copy Rate  
☐ Withdrawn (see below)  
☐ No Response from Applicant      ☐ Failure to Apply for Medicaid  
☐ Applicant's Request      ☐ Failure to Complete Application  
☐ Income over Program Level      ☐ Other: \_\_\_\_\_

544

Examined by \_\_\_\_\_ Date \_\_\_\_\_

Reviewed by \_\_\_\_\_ Date \_\_\_\_\_



**Erie County Health Department  
Physically Handicapped Children's Program  
APPLICATION FORM**

The following information is needed to determine your eligibility for participation in the Physically Handicapped Children's Program (PHCP). Please fill in ALL blanks, unless otherwise directed.

**PART 1 GENERAL INFORMATION**

Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_  
 Address \_\_\_\_\_ City/Town \_\_\_\_\_ Zip \_\_\_\_\_  
 Parent or Guardian's Name \_\_\_\_\_ Number of Persons in Household \_\_\_\_\_  
 Phone Numbers (Home) \_\_\_\_\_ (Business) \_\_\_\_\_

**PART 2 COVERAGE OF MEDICAL EXPENSES**

- A. Health Insurance: Are you covered by health insurance? YES NO. If "NO", go to "B. Medical Assistance Programs". If "YES", complete the following.  
 Do you pay health insurance premiums yourself? YES NO.  
 If "YES", how much do you pay per month? \$ \_\_\_\_\_

| Subscriber | Insurance Company | ID/Certif. No | Group | Class | Type | Date |
|------------|-------------------|---------------|-------|-------|------|------|
|            |                   |               |       |       |      |      |
|            |                   |               |       |       |      |      |

Does this insurance carry a Major Medical Rider? YES NO  
 Does this insurance carry a Prescription Drug Rider? YES NO

*Note: Proof of the Medical Insurance listed above must be provided to the Erie County Health Department along with this application.*

- B. Medical Assistance Programs: Are you receiving Medicaid, SSI or Public Assistance? YES NO  
 If "YES", please print the case numbers \_\_\_\_\_, then go to PART 4. If "NO", go to PART 3.

**PART 3 FINANCIAL STATUS (Income)**

Please fill in the information requested below. Include ALL sources of household income. You are required to provide a copy of your most recent federal tax return Form 1040 and copies of your last four (4) pay stubs as proof of income. You are also asked to send proof of any and all income listed below, but not reported on your income tax.

| Source                        | Name of Household Member | Gross Monthly Amount |
|-------------------------------|--------------------------|----------------------|
| Employer (Name)               |                          |                      |
| Employer (Name)               |                          |                      |
| Rental Income                 |                          |                      |
| Social Security               |                          |                      |
| Dividends, Bank Interest etc. |                          |                      |
| Child Support or Alimony      | 545                      |                      |
| Other (Identify)              |                          |                      |

# **PART 4      LIQUID ASSETS**

Please fill in the information requested below. Liquid assets include ALL bank accounts (savings, checking, CD's, etc.) as well as current cash value of stocks and bonds.

| Liquid Assets (savings, checking, stocks, etc.) | Name of Bank/Company | Balance/Cash Value |
|-------------------------------------------------|----------------------|--------------------|
|                                                 |                      |                    |
|                                                 |                      |                    |
|                                                 |                      |                    |
|                                                 |                      |                    |
| PHCP STAFF USE                                  |                      | TOT. _____         |

What is your monthly mortgage or rent payment? \$ \_\_\_\_\_.

## **PART 5      CERTIFICATION AND CONSENT** *(Please read carefully before you sign)*

**Certification:** In signing this application, I swear and affirm that the information that I have given to the Erie County Health Department is both complete and true to the best of my knowledge.

**Consent:** I understand that by signing this application form, I agree to any investigation made by the Erie County Health Department to verify or confirm the information I have given. If additional information is required, I will provide it.

**Agreement:** I agree to inform the Erie County Health Department promptly of any change in my income, living arrangements, address, or health insurance coverage. I agree to file any claims for health or accident insurance benefits, or any other resources, to which I am entitled. I agree to inform the Erie County Health Department of any lawsuit which involves the disability covered by this application, and of any resultant changes in health or accident insurance. I agree to turn over to the Erie County Health Department and/or providing verifiers any health insurance monies received by me for services covered under this application. I agree to comply with all requirements of any health insurance contract so that I might receive all benefits to which my child is entitled. *NOTE: With certain HMO Medical Coverage, in order to assure coverage, prior approval for services or a referral from your primary physician must be obtained before services are delivered. Often services can only be covered when delivered by participating providers.*

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## **PART 6      DISPOSITION** *(Completed by Program Staff)*

| PHCP STAFF USE      |  |
|---------------------|--|
| A. ANN.INC.         |  |
| B. L ASS X .52      |  |
| C. SBTOT A+B        |  |
| D. DED.             |  |
| E. ADJ.ANN.INC. C-D |  |
| F. LEVEL            |  |

☐ Approved PHL      ☐ After Insurance      ☐ No Insurance      ☐ % Copay Rate  
☐ Withdrawn (see below)  
☐ No Response from Applicant      ☐ Failure to Apply for Medicaid  
☐ Applicant's Request      ☐ Failure to Complete Application  
☐ Income over Program Level      ☐ Other: \_\_\_\_\_

Examined by \_\_\_\_\_ Date \_\_\_\_\_  
 Reviewed by \_\_\_\_\_ Date \_\_\_\_\_

**BEST COPY AVAILABLE**



## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

### DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

RE: \_\_\_\_\_

DOB: \_\_\_\_\_

Estimados Padres o Guardián,

El Programma para Niños con Incapacidad Física (PHCP) ha recibido una aplicación solicitado ayuda financiera para cubrir los gastos médicos del niño/niños mencionados arriba.

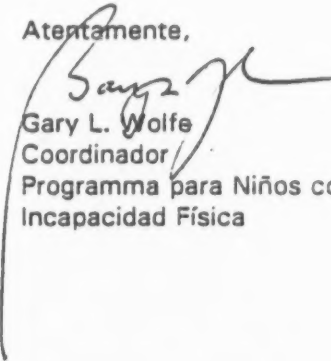
Hasta la fecha, no hemos recibido:

- \_\_\_ su formulario financiero completo
- \_\_\_ verificación de ingresos
- \_\_\_ copia de su tarjeta de seguro
- \_\_\_ otro: \_\_\_\_\_

Si Usted no responde antes de \_\_\_\_\_, su caso será retirado de nuestra programma. El pago de los servicios médicos, del equipo o de las provisiones solicitados se convertirá en su responsabilidad.

Si por alguna razón Usted no ha recibido una aplicación financiera del Programma PHCP, por favor póngase en contacto con \_\_\_\_\_ al 858-\_\_\_\_\_.

Atentamente,

  
Gary L. Wolfe  
Coordinador  
Programma para Niños con  
Incapacidad Física

*English on other side*



## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

### DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

RE: \_\_\_\_\_

DOB: \_\_\_\_\_

Dear Parent/Guardian,

The Physically Handicapped Children's Program (PHCP) has a current request for financial assistance to cover the above named child/children's medical expenses.

As of this date, we have not received:

\_\_\_\_\_ your completed financial form

\_\_\_\_\_ verification of income

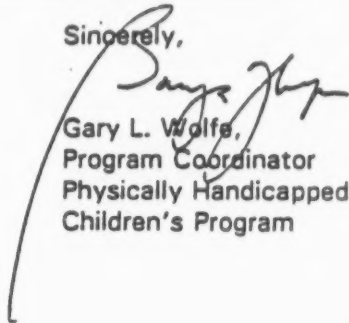
\_\_\_\_\_ copy of your insurance card

\_\_\_\_\_ other: \_\_\_\_\_

If you do not respond by \_\_\_\_\_ the case will be withdrawn from consideration. Payment for the requested medical services, equipment or supplies will become your responsibility.

If for some reason you have not received a financial application for the PHC Program, please contact \_\_\_\_\_ at 858-\_\_\_\_\_.

Sincerely,

  
Gary L. Wolfe,  
Program Coordinator  
Physically Handicapped  
Children's Program

GLW/my

FORM NO. PHCP-16  
(REV. 7/93)

548



# County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

## DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

RE: \_\_\_\_\_

DOB: \_\_\_\_\_

Estimados Padres o Guardián:

El Programa para Niños con Incapacidad Física (PHCP) ha recibido un formulario de \_\_\_\_\_ solicitando ayuda financiera par cubrir los servicios médicos, el equipo y/o las provisiones para el niño/niños mencioados arriba.

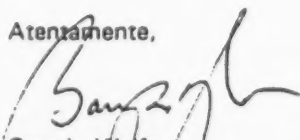
**SI QUIERE SER CONSIDERADO PARA RECIBIR AYUDA, USTED DEBE:**

- A. Completar, firmar y devolver la aplicación incluida aqui.
- B. Enviar la siguiente documentación sobre sus ingresos:
  - 1. Una  copia  del más reciente formulario 1040 de su declaración de impuestos,
  - 2. los cuatro (4) últimos talones de pago de su salario  Y
  - 3. prueba de cualquier otro ingreso mencionado en la aplicación (incluyendo renta, seguro social, pensión para niños, etc.)
- C. Enviar la documentación del seguro médico de su hijo/a (fotocopia de la tarjeta de seguro médico)

Enviar esta información a nuestra oficina en el sobre que incluimos aquí con nuestra dirección. Si usted no entrega esta información antes de \_\_\_\_\_, su solicitud podra ser retirada.

Si esta es la primera vez que aplica a nuestro programma, an Administrador de Casos ("Case Manager") de nueatra oficina le llamará y le dará una cita una entrevista. Si tiene alguna pregunta sobre esta aplicación, por favor llame a \_\_\_\_\_ al \_\_\_\_\_.

Atentamente,

  
Gary L. Wolfe,  
Coordinador  
Programa para Niños con  
Incapcidad Física

*English on other side*



# County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

## DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

RE: \_\_\_\_\_

D.O.B. \_\_\_\_\_

Dear Parent/Guardian:

The Physically Handicapped Children's Program (PHCP) has received a request from \_\_\_\_\_ for financial assistance to cover medical services, equipment and/or supplies for the above named child/children.

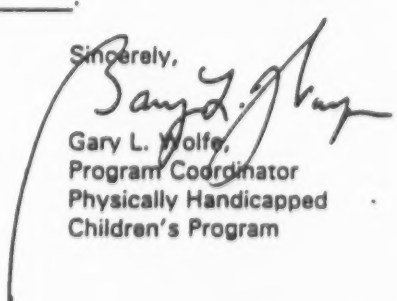
### IN ORDER TO BE CONSIDERED FOR ASSISTANCE, YOU MUST:

- A. Complete, sign and return the enclosed application.
- B. Send the following documentation of income:
  - 1. A copy of your most current 1040 income tax form AND
  - 2. your last four (4) paystubs, AND
  - 3. proof of all other income reported on the application including rent, social security, child support, etc.)
- C. Send documentation of your child's health insurance (photocopy of the health insurance card.)

Forward this information to our office in the enclosed self-address envelope. FAILURE TO PROVIDE THIS INFORMATION TO US BY \_\_\_\_\_ MAY RESULT IN YOUR REQUEST BEING WITHDRAWN.

If this is your first application to our program, you will be contacted by a Case Manager from our office to set up an appointment for an interview. If you have any questions regarding this application, please call \_\_\_\_\_ at \_\_\_\_\_.

Sincerely,

  
Gary L. Wolfe,  
Program Coordinator  
Physically Handicapped  
Children's Program

GLW/maa  
Enclosures

FORM NO. PHCP-15 (rev. 7/93)

550



29 de agosto de 1994

RE:  
DOB:  
EFF. DATE:

Estimados Padres o Guardián,

La aplicación solicitando el pago por parte del Programa para Niños con Incapacidad Física (PHCP) en favor de ha sido negada.

La razón por la cual su solicitud fue negada es:

Una copia de esta carta se enviará a médico de su hijo/a.

Si Yd. desea solicitar un audiencia sobre esta decisión, for favor entregue su solicitud por escrito **en treinta (30) días** desde la fecha de esta carta. Su solicitud debe explicar exactamente cuál es la razón de su queja y debe estar acompañada por documentos que confirmen su argumento.

Por favor envíe sus queja a: Comissioner of Health, 95 Franklin Street, Buffalo, New York, 14202.

Atentamente,

Gary L. Wolfe  
Coordinador  
Programa para Niños con  
Incapacidad Física

*English on other side*



## County of Erie

DENNIS T. GORSKI  
COUNTY EXECUTIVE

### DEPARTMENT OF HEALTH

ARNOLD N. LUBIN, M.D.  
COMMISSIONER OF HEALTH

August 29, 1994

RE:  
DOB:  
EFF.DATE

Dear Parent/Guardian:

The application requesting payment from the Physically Handicapped Children's Program (PHCP) for has been DENIED.

The reason for this denial is:

A copy of this letter is being sent to your child's physician.

If you wish to request a hearing regarding this decision, please submit your written request within thirty (30) days of the date of this letter. Your request must specify the exact nature of your complaint and should be accompanied by copies of supporting documents.

Please address your complaints to: Commissioner of Health, 95 Franklin Street, Buffalo, New York, 14202.

Sincerely,

Gary L. Wolfe,  
Program Coordinator  
Physically Handicapped  
Children's Program

GLW/my/ms  
CC: Physician:  
File

*Español al reverso*

552

## **Managing care for a child with special health needs can be a demanding job!**

**There are so many things to consider!**

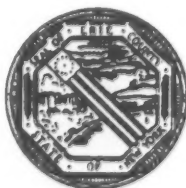
... getting adequate medical care ... figuring out  
health insurance coverage ... meeting family financial needs ...  
finding services in the community ...  
picking education programs ... knowing what public  
benefits are available ... dealing with government red tape ...  
finding emotional support

**There is help available!**

The Erie County Health Department's Physically Handicapped Children's Program (PHCP) can help you in putting the pieces together as you meet the demands of caring for your child.

Through its Case Management Program, Erie County PHCP will work with families to assist them in identifying concerns, addressing problem areas, setting goals, and both finding and coordinating needed services.

**For more information call 858-8565**



**DENNIS T. GORSKI**  
County Executive

**ARNOLD LUBIN, M.D.**  
Commissioner of Health

*Erie County does not discriminate on account of age, sex, race, religion, handicap, national origin, color, sexual orientation, marital status or sponsor.*

**BEST COPY AVAILABLE**

## **¡ Manejar a un niño con necesidades de salud especiales puede ser un trabajo muy exigente !**

### **¡ Hay tantas cosas que tomar en cuenta !**

... conseguir el cuido médico ádecuado ... encontrar la cobertura de  
seguro médico ... cumplir con las necesidades finnancieras de la familia ...  
encontrar servicios en la comunidad ...  
escoger programas educativos ... conocer qué beneficios públicos están  
disponibles ... tratar con el trámite burocrático del gobierno ...  
encontrar apoyo emocional

### **¡ Usted tiene ayuda a su disposición !**

El Programa para niños con Incapacidad Fisica del Condado de Erie  
(PHCP) puede aydarie a organizarse para cumplir con las necesidades de  
cuidado de su hijo/a.

A través de su Programa de Manejo de Casos, le programa PHCP del  
Condado de Erie trabajará con familias para ayudaries a identificar sus  
preocupaciones, enfrentar las áreas problemáticas, establecer objetivos y  
encontrar y coordinar los servicios necesarios.

**Para más información, llame 858-8565**



**DENNIS T. GORSKI**  
Ejecutivo del Condado

**ARNOLD LUBIN, M.D.**  
Comisionado de Salud

*El Condado de Erie no discrimina en base a edad, sexo, raza, religión, incapacidad,  
nacionalidad, color, orientación sexual, estado civil o auspiciador.*